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An investigation of the influence of an online patient diary on the health outcomes and experiences of people with chronic obstructive pulmonary disease (COPD) participating in a mentored self-management clinical controlled trial.

By

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Elizabeth Cummings

October 2008

Abstract

This research thesis investigates the influence of an online patient diary on the health outcomes and experiences of people with chronic obstructive pulmonary disease (COPD) participating in a mentored self-management clinical controlled trial. The trial primarily aimed to assess clinical outcomes resulting from changes in participants' self-efficacy for self-management supported by telephone based mentoring and daily symptom self-monitoring.

Although most evaluations of chronic disease self-management (CDSM) interventions report some benefit, the variety of methodologies and assessment procedures used make comparisons of efficacy difficult and highlight the complexity and uncertainty associated with supporting CDSM. Linked to many of these approaches are also claims about the positive role of information and communication technologies (ICTs), however numerous questions remain over the nature and reliability of the measures used and their relationships to patient outcomes and experiences at individual and cohort levels. At a practical level, there remains limited knowledge on how patients experience CDSM interventions and what factors frame and/or constrain their involvement and ability to derive benefit. There is also a need for more sophisticated approaches to understand and evaluate the influence of ICTs on patients engaged in CDSM interventions. Approaches that can meaningfully explore the gap between assessments of ICT benefit for a cohort of patients versus those for an individual patient.

The methodology used in this research adopted a subjective ontology and employed an interpretive epistemology. The research strategy involved a three phase approach. Phase 1 examined quantitative data from the controlled trial to establish the effect of the overall intervention on clinical and other outcome measures and to identify and validate data on participants selected for qualitative follow-up. Phase 2 conducted semi-structured interviews to form twelve participant cases (six patients who had used the online patient diary and six who had not). For each case, interviews were conducted with the participant, their primary mentor and the trial research assistant to form a 'care triad' (thirty-six interviews in total). Phase 3 combined data from phases one and two for each of the twelve cases to explore in detail the inter-relationships amongst factors (including the online patient diary) influencing patient's health outcomes and experiences over the duration of the trial.

Phase 1 analysis involved descriptive statistical analysis of the effect of the trial on a number of clinical and other outcome measures at 3 levels: intervention [N=55] versus control group [N=51]; intervention group (ICT adopters [N=20] versus ICT non-adopters [N=35]); and, amongst participants selected for interview (ICT adopters [N=6] and ICT non-adopters [N=6]). Phase 2 qualitative analysis coded all thirty six interview transcripts and drawing on the principles of grounded theory generated a series of core categories identifying concepts and themes across the twelve cases including those relating to patients: understanding of the trial; impact of their social environment; the severity of their disease; and, the impact of a computer and online patient diary. Phase 3 constructed in-depth case studies of the twelve individual participants from the quantitative and qualitative data collected in the previous phases. These case studies provided a means for exploring the relationships between individual differences and the impact of computers and online patient diaries.

Results from phase 1 included that the clinical controlled trial had no discernible effect upon the clinical outcomes at any of the three levels. However, there was a positive effect at all levels on the quality of life outcome scores. Phase 1 also highlighted that based on these quantitative measures alone, the use of the online patient diary appeared to decrease the efficacy of the intervention. Results from phase 2 however included the insight that the use of the online patient diary for some participants actually increased their understanding of their symptoms and the effects of external factors upon their health and ability to cope. These apparently conflicting results highlight the benefits of utilising both quantitative and qualitative analysis. Phase 2 also provided some insight into the inter-relationships amongst factors including how the computer and online patient diary influenced individual patient's outcomes and experiences. Further insights were also generated by combining data from phases 1 and 2. In this regard, results from phase 3 included the significant insight that for some participants key benefits arise from access and use of the computer rather than the online patient diary per se. These benefits include changes in individual participants' ability to communicate more widely and easily with family, peers and clinicians, their social status within their families and social groups, a reduction in perceived levels of isolation and increased confidence about themselves and their capabilities to manage their illness and its effects.

This research thesis makes contributions to knowledge at a number of levels. At the substantive level, by providing a detailed investigation of the influence of ICTs on patients within a clinical controlled trial this research has enhanced understanding of how patients experience CDSM interventions and what factors frame and/or constrain their involvement and ability to derive benefit. At the methodological level, this thesis has presented an approach that by drawing on and combining quantitative and qualitative data has been able to meaningfully explore the gap between assessments of ICT benefit for a cohort of patients versus those for an individual patient. At the theoretical level, this research thesis has been able to highlight that current clinical and technical evaluation paradigms have their limitations where patients are encouraged to be active participants. This in-turn enables clearer reflection on what is meant by 'individualised care' and 'empowered patients' in the era of eHealth.

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Acronyms

AHIC	Australian Health Information Council
ALLS	Adult Literacy and Life Skills Survey
BCG	Boston Consulting Group
BDI	Baseline Dyspnea Indexes
BMI	Body Mass Index
CDSM	Chronic Disease Self-Management
CDSMP	Chronic Disease Self-Management Program (Stanford)
CHN	Community Health Nurse
COPD	Chronic Obstructive Pulmonary Disease
EBM	Evidence-Based Medicine
FDD	Feature Driven Development
FEF 25-75	Forced Expiratory Flow 25-75%
FEV1	Forced Expiratory Volume in 1 second
FEV1/FVC ratio	Forced expiratory volume/Forced vital capacity ratio
GDP	Gross Domestic Product
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HCI	Human Computer Interaction
ICT	Information and Communications Technology
IS	Information Systems
ISDM	information systems development methodologies
IT	Information Technology
IVR	Interactive Voice Response
MCS	Mental Component Summary
MI	Motivational Interviewing
MMSE	Mini Mental State Examination
MRC	Medical Research Council
NHIG	National Health Information Group
PACS	Picture Archiving and Communication Systems
PCS	Physical Component Summary
PD	Participatory Design
RCT	Randomised Controlled Trial
SLT	Social Learning Theory

SMS	Short Message Service
TAM	Technology Acceptance Model
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TTMC	Trans-theoretical Model of Change
UCD	User-Centred Design
XP	Extreme Programming

Table of Contents

Table of Tables

Table of Figures

Chapter 1 Introduction

> The purpose of health care systems are to reduce continually the burden of illness, injury, and disability, and to improve the health status and function of the people (Berwick, 2004).

1.1 Introduction

This thesis investigates the influence of an online patient diary on the health outcomes and experiences of people with chronic obstructive pulmonary disease (COPD) participating in a mentored self-management clinical controlled trial.

This chapter provides a summary of the background to the thesis and identifies both the research questions and objectives. It highlights the contribution the investigation makes to the theory and practice of health informatics research in the area of evaluation of patient-centred information and communication technology (ICT) tools within the home or community setting.

This chapter is divided into the following sections:

- Section 1.2 provides a background to the concerns that frame this research and outlines the conceptual framework within which the research was conducted;
- Section 1.3 introduces the research problem, primary research questions and research objectives. It discusses the scope of this research including participant selection and location as well as the data collection employed.
- Section 1.4 presents the contributions of this thesis to knowledge and practice in IS research. This section outlines contributions at the substantive, methodological and theoretical levels.
- Section 1.5 presents a review of the thesis structure outlining the remaining chapters.
- Section 1.6 provides a summary reflection of these sections.

1.2 Background

At the broadest level, the background to this research involves a number of practical and conceptual concerns arising within the research domains of patient-centred health informatics, evaluation methodologies and healthcare delivery.

Health research projects involving interventions, including those involving ICTs, have tended to be based upon random controlled trials (RCT) and evaluated based on clinical outcomes and/or quantitative measures of ICT adoption and use. More recently however a body of evidence has begun to emerge that raises questions about not just the reliability of these measures per se but also about what they miss in terms of individual patient experiences, priorities and perceptions (Berwick, 2004; Muir Gray, 2004a).

The views of patients have become increasingly important because of the shift in the burden of healthcare from acute to chronic and acute to the primary sector because of ageing populations. They are also important because from a health informatics

perspective failure to take into account these individual differences may be a major contributing factor in the high incidence of health informatics project failures.

Although it is also important to consider the possibility that limitations in current evaluation methods may mean that some projects currently viewed as failures may have been very successful for patients. Similarly projects that are currently considered successful may have little meaning for patients/participants which in turn may account for the lack of continuity and/or sustainability witnessed with many health and eHealth projects.

These concerns are framed by the case study that forms the basis of this research. The case study was conducted within an exploratory study to assist chronically ill patients to increase their ability to self-manage their condition at home in partnership with mentors and an optional online patient diary. Thus this research operates within the context of questions that arise within the following broad research domains:

1. Chronic Disease Self-Management (CDSM);
2. eHealth Evaluation; and
3. Health Outcome Evaluation

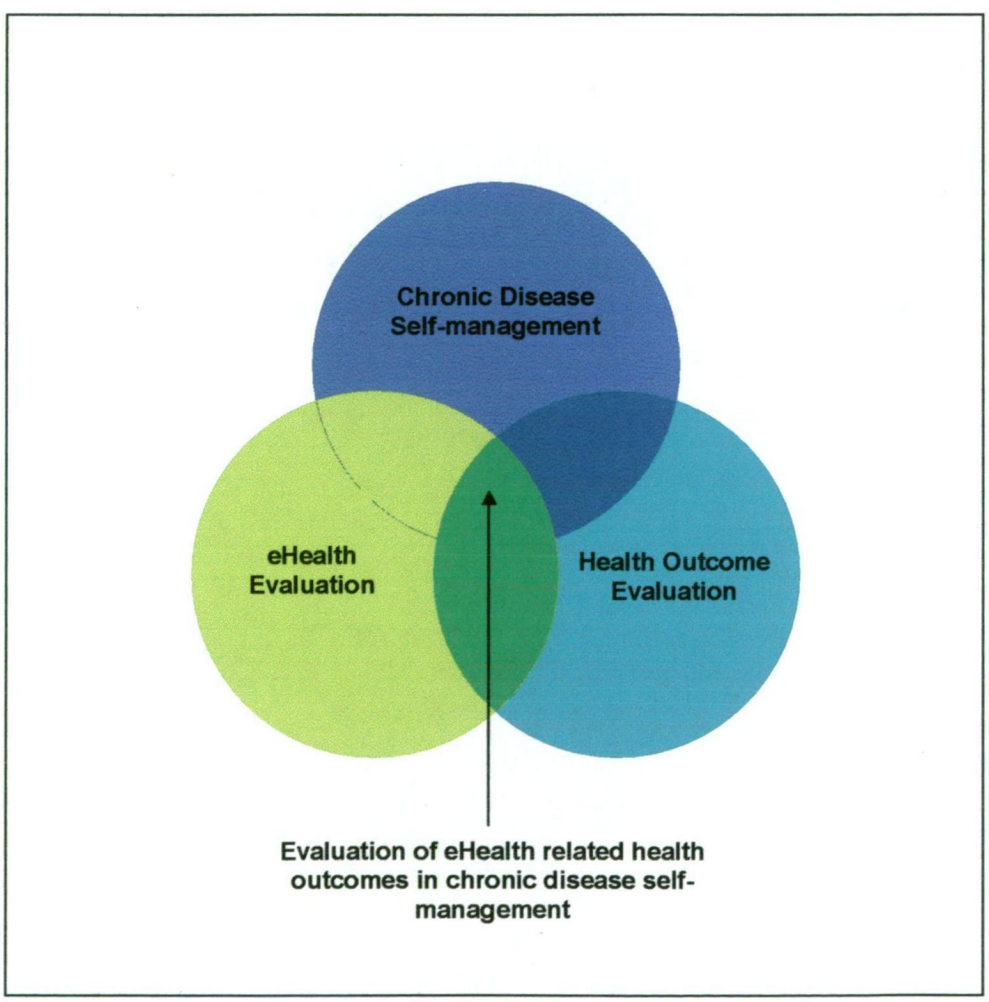

Figure 1.1: Location of research within broader discourses

Healthcare systems in Australia and across the developed world are under stress. As medical innovations continue to enhance our ability to fight disease and prolong life, ageing populations have transformed the nature of and the demand for increasingly expensive medical procedures, medications and health care services. Looking to the future, without significant change Australia's health care system is likely to experience increasing costs, growing complexity in health service demands and escalating work-loads on health professionals accompanied by declining overall system affordability and reduced equity of, and access to, quality care for many Australians.

In this context, it is perhaps not surprising that health reform has been a major item on political and policy agendas. Alongside changes to Medicare, health system funding arrangements, medical insurances and the legal and regulatory environment, e-health initiatives have been identified as major drivers for stimulating the changes necessary to address this crisis. By opening up opportunities for increased information access, cost effectiveness, improved information delivery, update and evaluation the economic case for more ICTs is strong. However, this deployment also raises a number of socio-technical, clinical and legal challenges that have become increasingly evident as the implementation of more sophisticated ICT solutions have met with mixed success or failed to generate their forecast benefits.

eHealth innovations clearly have huge potential to support a 'better connected health system' and the realisation of a vision of future health care system that is more efficient, safer, knowledge-based, patient-centred and that provides universal, accessible and affordable care. However, many approaches to e-health continue to downplay existing levels of complexity and uncertainty that exist in the delivery of health care services and make problematic assumptions about how ICTs will benefit patients, health professionals and the health care system as a whole (Cummings & Turner, 2007).

Significantly, recent strategic evaluations of research reporting positive benefits from the introduction of ICTs into health have begun to question their reliability and revealed many measures of success have little to do with improvements in care or patient outcomes (Wyatt, 2004). At the broadest level, the conduct of this case study the research aims to contribute to these discussions and explore some of the assumptions that underpin much of the push towards the implementation of eHealth solutions, and in particular the often uncontested presumption that the introduction of ICTs to healthcare will axiomatically improves patient outcomes.

More specifically, the case study also recognises that in response to the growing incidence of chronic illness, one set of approaches seeks to involve patients directly in their own care by improving their capacity to self-manage. These approaches assume that this involvement will be positive in terms of quality of care and health outcomes. While most evaluations of these approaches report some benefit, the variety of methodologies and assessment procedures used make comparisons of efficacy difficult and highlight the complexity and uncertainty associated with supporting self-management of chronic illness (Warsi, Wang, LaValley, & Avorn, 2004). Linked to these approaches are claims about the positive role ICTs can also have on the self-management of chronic illness (Celler, Lovell, & Basilakis, 2003). By improving information access, information delivery, update and evaluation ICTs clearly have potential. However, there is a tendency in the claims that are made about the benefits to marginalise the socio-technical, clinical and legal challenges that need to be

overcome. More broadly, recent strategic evaluations of research reporting positive benefits from the introduction of ICTs into health indicate serious questions that need to be answered regarding their reliability and/or how many measures of success which have been used have little to do with improvements in patient care or outcomes (Wyatt, 2004).

Combined these discussions indicate that technology support for the self-management of chronic illness requires care. Advocating that the development, implementation and evaluation of the technology should be based on a detailed understanding of users, their needs, experiences and complex interactions with health professionals, the health system and the wider environment is easy - actually engaging in this process has proven considerably more difficult.

At a conceptual level critical reflection on terms like self-efficacy and self-management reveal implicit assumptions about the nature and role of patients and health professionals in chronic disease management. Supporting patients in acquiring confidence in problem-solving and decision-making around their illness as a means to positively impact on their health status is a worthy goal but how are the boundaries of empowerment played out with health professionals in practice? Issues of power and empowerment are also played out in the development, implementation and evaluation of technologies that aspire to be 'patient-centred'.

At a practical level, how are patients involved and what factors frame and/or constrain this involvement during development, implementation and evaluation of these technologies? There is also a need to consider the interaction between the discourses on self-management and patient-centred systems particularly in terms of differentiating and evaluating their respective influences on patients' health outcomes. There is also a need to consider underlying assumptions made about the role, impact and importance of information; given that it is only one factor among many that influence health attitudes, perceptions, actions and outcomes. More specifically, as interventions supporting self-management become more common there is a need to ponder how assessments of benefit in terms of a cohort of participants inform us about individual patient's experience and what this implies for terms like 'individualised care' or 'patient empowerment' (Muir Gray, 2004b).

Finally, the dominance of RCTs as a means of evaluating health care interventions is of concern (Grossman & Mackenzie, 2005). While often patient stories are more powerful than the evidence (Newman, 2003) in the era of evidence based medicine there remains a conflict between statistical evidence and the individual's experience. There is a school of belief that there exists an "hierarchy of evidence" where the RCT is the most scientific and rigorous study design available and so provides the best evidence (Bluhm, 2005; Grossman & Mackenzie, 2005). These beliefs have also penetrated the health informatics discipline where quantitative methods, including RCTs, have until recently been considered the evaluation method of choice for evaluating health information systems (Stoop & Berg, 2003). This in-turn raises fundamental questions about how this primacy of evaluation measures masks, marginalises or ignores individual patient experiences.

1.3 Research Problem

This research seeks to explore the impact of the introduction of an online patient diary on the participants' health outcomes and experiences within a mentored self-management clinical controlled trial.

It is evident that there are some deficiencies within the current evaluation framework used to evaluate clinical interventions. This research argues that it is important to look at not only the general measurable view of benefits but also the relationships between events that are less susceptible to formal measurement but that may provide further insights into the benefits gained from participation in the project, benefits that often remain invisible due to the nature of dominant evaluation frameworks. This information and insights can only be gained by exploring the individual's experiences.

Currently health outcomes are seen as independent, measurable entities. They are included in most health evaluation frameworks and give a good indication of change for a whole population but they frequently fail to provide insight into the reason behind the changes at an individual. This research is looking at both the change reported over time in relation to the health outcome data, supplemented with interview data to illuminate and explore the social and personal effects from the project on individual participants with the aim of generating insights into how these effects influence health outcomes.

The interplay of social and psychological factors and their impact upon people's self-perceived health status has been acknowledged for a number of years. However, it is rare for this to be considered in the context of a clinical intervention let alone a complex self-monitoring intervention with an IT component. In this context, this research examines how individual participants interpret and discuss their various experiences and the different ways in which these play out for these individuals as a means of gaining insight into what triggers different behaviours. Through identifying different behaviours, and relationships between behaviours and/or experiences, it is anticipated that insights will be generated that will improve the processes used to support self-management amongst COPD patients.

Similarly, ICT evaluation techniques frequently deal with the technological efficiency or acceptance but rarely examine in any detail the interplay of personal factors that make up an individual's technology experiences. This research explores the interplay of life factors that may have a significant impact upon how and why people may or may not chose to adopt and subsequently use technologies as well as the effect these decisions and uses ultimately have on personal outcomes

Within this research case study an opportunity is provided to examine the experiences of the individual in relation to their disease and life in response to the intervention across a cohort of patients some of whom did and some who did not adopt and use an on-line patient diary as part of the intervention. More specifically this case study opens up the possibility to explore in detail at individual and cohort level factors that may influence decisions to use ICT tools and how experience of the online patient diary may influence an individual's overall experience within the project. .

1.3.1 Research Aims

1. To investigate the experiences of participants in relation to the adoption and use of an online patient diary within a programme developed to assist people with chronic illness improve their ability to self-manage their condition.
2. To examine the development of self-efficacy for self-management amongst a subset of the participants in the Pathways Home Project
3. To investigate the non-mandatory adoption of the online patient diary and associated impacts of the adoption.
4. To develop an understanding of methods to aid meaningful evaluation of the impact, role and/or benefit of the ICT systems in the development of self-efficacy and self-management.

1.3.2 Research Questions and Objectives

The following research questions and related objectives were identified.

Research Question 1

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

RQ1: RO1 To describe the impact of the overall intervention on health outcomes; and

RQ1: RO2 To explore the impact of the online patient diary on health outcomes within the intervention.

Research Question 2

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO1 To qualitatively explore the impact of the online patient diary; and

RQ2: RO2 To explore the wider influence of the online patient diary on individual patients' experiences through an holistic examination of factors and their interactions revealed by both the clinical trial and qualitative data.

1.3.3 Research Approach

This research was conducted within a clinical controlled trial, randomised by domicile, which aimed to improve the self-efficacy for self-management of participants with COPD. The trial intervention involved provision of telephone based self-management mentoring by community health nurses combined with symptom monitoring diaries, either paper-based or online.

The research was conducted in three phases. The first phase involved conducting a brief analysis using descriptive statistics, from the clinical controlled trial, to understand the clinical, self-efficacy and quality of life outcomes on three sub-groupings: intervention [N=55] versus control group [N=51]; intervention group (ICT

adopters [N=20] versus ICT non-adopters [N=35]); and, amongst participants selected for interview (ICT adopters [N=6] and ICT non-adopters [N=6]). This phase addressed the first research question.

The second phase involved conducting and analysing semi-structured interviews to form twelve participant cases (six patients who had used the online patient diary and six who had not). For each case, interviews were conducted with the participant, their primary mentor and the trial research assistant to form a 'care triad' (thirty-six interviews in total).

The interviews were analysed drawing on the principles of grounded theory generated a series of core categories identifying concepts and themes across the twelve cases. These triad interviews were initially used within each group of 6 and 6 to look at differences in the ways they described their experiences, and the experiences of the participant, within the programme and any changes in their health behaviours in response to their involvement. This phase addresses the first objective of research question 2.

Finally twelve individual case studies, one for each of the twelve triads, were developed to explore the experiences of the individuals in greater detail and over time. In constructing these case studies both the quantitative and qualitative data from the previous analyses was used to provide a more complete picture of the individual participants' experiences from a number of perspectives. Due to the depth of analysis conducted only four examples of these individual case studies are presented within the thesis although all findings are presented. The four cases provide examples of cases where the following different experiences are demonstrated:

- No adoption of the online patient diary and little evidence of change in self-management ability,
- No adoption of the online patient diary and major changes in health behaviours,
- Adoption of the online patient diary but reverted to paper based diary with evidence of change in self-management ability, and
- Adoption of the online patient diary and evidence of a major change in health behaviours.

Through developing and employing this methodology it has been possible to investigate more fully the individual experiences of people with chronic diseases whilst undertaking a self-management programme and to meaningfully identify and evaluate the influence of the adoption and use of the online patient diary on participants' health outcomes and experiences.

1.4 Summary of Contribution

Current health informatics research work requires researchers to grapple directly with a range of competing paradigms that have different philosophies and methods that influence the data, and value judgements that are deemed relevant. Into this context new and emerging technologies are being introduced to further compound the complexity faced by researchers. In this study an additional layer of complexity is added by direct involvement of people with chronic diseases and their families. As a result this research emphasises the need for a reassessment of the way researchers and

health care providers conceptualise the 'patient'. Through this project the concept of self-monitoring for self-management has been complemented by the provision of an online patient diary enabling participants to observe and interpret their symptoms over time and to potentially enhance their understanding of factors that impact upon their individual condition. This new conceptualisation of the patient as an active and knowledgeable participant in their own care will need to be incorporated into health care models and perhaps most particularly those involving health informatics developments if a sustainable model of care for people with chronic diseases in the community is to be developed.

Thus this research provides evidence that when developing ICT tools for patients to use in self-monitoring and self-management it is critical to understand the people, their families and the communities involved along with the social, psychological and economic factors that impact upon these people's abilities to embrace these changes. A focus solely upon the clinical factors of their disease can no longer be deemed sufficient if patients are to be truly engaged and active co-participants in their own care.

From an information systems perspective it is noticeable that much of the current health informatics theory is based upon measuring and evaluating the impact of ICTs within the constraints of clearly defined organisations. While these models may have merit in these homogeneous environments they are less well suited to evaluate the impact of ICTs introduced in voluntary ways (non-mandatory) and/or into the homes of individual patients. Conventional evaluation approaches have been appropriate until now as there has been an emphasis within health informatics upon the introduction of information systems into institutional settings, primarily hospitals. As the focus, both in terms of health care and health informatics, moves towards care outside institutional boundaries new challenges emerge. There can no longer be mandatory use of systems, people will adopt and use systems in ways that suit themselves and their lifestyles and not necessarily as anticipated by clinicians or information technology (IT) professionals. This leads to the requirement to change the ways in which the impacts and benefits of these systems are evaluated.

In this context, this research provides insights into some of the factors that have led participants with chronic illness to use a non mandatory online patient diary but also, and no less importantly, it has provided some insights into why people choose not to use these tools. As a result it emerges that when evaluating the efficacy and impact of IT tools upon people living in their own homes it is essential to consider the social setting, disease type, the ways in which the IT tools are utilised and also why they are not utilised and by whom.

At the broadest level this research suggests that conceptual models underpinning the conduct of clinical trials are challenged by data generated from a more detailed analysis of the range and depth of impacts experienced by individual patients. This thesis also demonstrates the potential value of carefully combining both conventional trial models and qualitative research models within a subjective ontology and interpretivist epistemology. This approach can provide a rich model for exploring impacts at cohort, group and individual levels. Through expanding the conceptual models of clinical controlled trials in this way it is possible to enhance the breadth of understanding of the impacts of interventions

This research is also able to contribute to re-aligning conceptual models of patients as passive recipients of care who conform to the expectations of doctors, act in predictable ways and share a common value structure by revealing these perspectives as outdated and inappropriate for understanding the current and future roles and experiences of patients living with chronic illnesses in the community.

At the methodology level, this thesis has utilised both quantitative and qualitative data across cohorts, groups and individuals to build an expansive, deep and rich view of participants' experiences and outcomes within a controlled trial. Through combining the analysis of the clinical controlled trial data with interview data this research has demonstrated a method which provides the researcher with the ability to gain insights at multiple levels of abstraction.

As part of this approach this research has contributed insights on the use of triad interviews to triangulate the findings of interview data. The ability to use the triad interviews at both group and individual levels is demonstrated in Chapter 6.

At a substantive level this research has provided insights into the impact of an online patient diary within the confines of a clinical controlled trial of an intervention to improve participants' self-efficacy for self-management of their chronic obstructive pulmonary disease. These insights are summarised below:

This thesis has provided evidence that challenges the assumption that the impact of introducing an IT tool can be separated from other life and/or project influences and so it can be measured easily. The measurement of the impact of a non-mandatory IT tool is in itself a complex undertaking. However, to understand the impact that such a tool can have within the confines of a clinical controlled trial of an intervention to improve participants' self-efficacy for self-management of their COPD is extremely complex. The research has demonstrated that there is no standard response to the introduction of such a tool and for researchers undertaking similar types of research it is essential to use alternative data collection techniques in order to explore the phenomenon in greater depth.

This research has provided insights that challenge the assumptions that an IT tool for self-monitoring will be used or that through self-monitoring people will axiomatically learn to understand and manage their illness. These assumptions are problematic as they assume that people all have similar responses to the experience of having a chronic illness and that this response is a desire to understand their illness and become actively involved in the management of their illness. They also assume that people are interested in and able to learn how to utilise IT tools to monitor their condition. Through this research it has been demonstrated that there is a wide range of responses to this type of intervention and it is essential to provide a range of tools to participants and provide for the possibility of more than one tool being used dependent upon personal circumstances and preferences. It is also important for health informatics researchers to remember that paper is also a data collection tool and sometimes not using an IT tool is a valid outcome.

This research has illuminated the difficulties that will be experienced by health informatics specialists when implementing eHealth solutions into peoples' homes and into the community. The research has demonstrated the limited abilities and experiences that are evident in many members of the community who suffer from COPD. These people do not have access to, nor experience with computers. Significant time, money and effort are required to enable similar groups to gain access

to any potential benefits from the use of eHealth applications. It is essential for the future of community health informatics and for the sustainability of health care that significant investment is made into providing these resources for all and ensuring now that we do not establish an eHealth divide that further compounds existing inequalities in access to and use of health care services.

When evaluating the impact of an IT tool it is relatively easy to evaluate it in terms of the prescribed activities but the practical impacts are less visible although frequently of more importance at the individual level. In other words, it is easy to measure the number of times a person has completed a diary or looked at the feedback sheet or even utilised what they have seen to alter their health management. However, the evaluation of the effects or impact of less tangible or indirect changes is more difficult. This research has highlighted the interconnectedness of the relationships between the participant's social, economic psychological and health related factors and their ability or desire to adopt and learn to use a self-monitoring tool, be it technology based or not.

This research has highlighted a number of questions that should be considered when commencing or evaluating the impact of a clinical controlled trial. These questions include:

- Why are the participants signing-up for the trial?
- What is their level of understanding of the trial purpose, processes and outcomes?
- How does the participant's relationship with their health care provider(s) impact on their decision to enrol? and
- What is the potential impact of the answers to each of these questions upon each other and the participants?

This research has demonstrated that for this group of people with COPD it is important that the trial is structured in a manner that does not lock them into the paradigm of the research team and fails to make use of and acknowledge their own life experiences, attitudes, thoughts and concerns. The research design must be flexible enough to enable the individual's pre-developed coping mechanisms to be incorporated into the activities and not be underestimated, undermined or discarded.

Within research trials it is advisable to utilise validated and standardised evaluation instruments. The trial within which this research was located used instruments of this type. However, there are limitations to these instruments in particular the fact that through being generalisable they lose the ability to be individualised. When designing a trial it is difficult to conceptualise the possible range of responses of participants to any single intervention. This difficulty is compounded when the intervention is not able to be isolated from other external factors or influences, for example social settings. Thus the research has demonstrated the need to not only question the strength of these measures but also to provide alternative methods through which to explore the impacts of interventions.

Finally, this research has highlighted to the researcher the questions of the morality, difficulty and ethics of withdrawing such an intervention at the conclusion of a trial. Despite the fact that participants enter into such trials understanding that the intervention will be withdrawn after a certain point it is not possible for them or the

researcher to fully understand the impact of this withdrawal. For particularly vulnerable participant, as many of these were, it is possible for a dependence relationship to form both with the mentor and with the online patient diary. So it is important to provide a withdrawal plan and a follow-up evaluation to ensure that the participants come to no harm as a result of the withdrawal of the intervention.

1.5 Summary of Chapters

This section provides a brief overview of each of the subsequent chapters contained within this thesis.

1.5.1 Chapter 2 – Pathways Home for Respiratory Illness Project

Chapter 2 provides a detailed description of the Pathways Home for Respiratory Illness Project within which the research was located. The project was a clinical controlled trial, randomised by domicile, and with an intervention which involved provision of telephone based self-management mentoring by community health nurses combined with symptom monitoring diaries, either paper-based or online. The trial used validated quantitative measures of clinical outcomes, self-efficacy for self-management and quality of life survey instruments as evaluation techniques. The development and implementation of the ICT support for the project is also described in this chapter.

1.5.2 Chapter 3 – Literature Review

Chapter 3 provides an overview and critical review of the core literature in relation to the key domain areas that are relevant to this research. It commences by providing some insights into the issues of healthcare system pressures in particular the increasing rates of chronic disease in our communities, changing models of care and the introduction of ICTs into healthcare. It then introduces the core CDSM concepts and describes some of the programmes currently being used, with particular emphasis upon those in use in Australia. The chapter then provides insights into the area of eHealth evaluation. This is a very broad area and so key literature and concepts are described in terms of two types of evaluation, summative and formative. Finally it provides an investigation of some of the methods employed in evaluation of health outcome. There is a vast array of literature on the evaluation of health outcomes and so this section has been tailored to focus upon those most directly relevant to the current research.

1.5.3 Chapter 4 – Research Methodology

Chapter 4 of the thesis describes the research methods used to conduct the research. The chapter addresses the philosophical stance adopted, the research strategy and procedures employed, the data analysis techniques applied and outlines the approach to the interpretation and discussion of the research. This chapter introduces the concept of triad interviews and discusses the method by which they can be used to triangulate interview data. Individual semi-structured interviews were conducted with a group of project participants, their primary mentors and the research assistant who visited participants in their homes – this formed the care triad. The triad interviews were examined in conjunction with survey data to provide a broad picture of

participants' experiences within the mentored self-management program both with and without the use of the online patient diary.

1.5.4 Chapter 5 – Data Analysis

Chapter 5 provides an in-depth discussion of analysis of the data that emerged from the clinical controlled trial data. The data analysis was conducted in using descriptive statistics to provide an understanding of the total population involved in the Pathways Home for Respiratory Illness project (control versus intervention); the online patient diary users and non-users; and also the sub-groups used within this research. By using descriptive statistics in this way it is possible to demonstrate the limitations of the current dominant paradigm of using RCTs to evaluate health care interventions.

1.5.5 Chapter 6 – Triad Interview Analysis

Chapter 6 provides an in-depth discussion of the coding process involved in the analysis of the triad interviews. The core categories are explored in detail and the relationships between the core categories are identified. Finally a cross group analysis of the triad interview data is presented to determine similarities and differences between the two groups included in the research, those who adopted the online patient diary and those who did not.

1.5.6 Chapter 7 – Individual Case Study Analysis

Chapter 7 provides three examples of the comprehensive case studies developed to explore the individual experiences of each participant. These case studies provide an analysis of the combined data, descriptive statistics and qualitative interview data, to provide a broader picture of the individual cases. This allowed the researcher to explore in detail the inter-relationships amongst factors (including the online patient diary) influencing patient's health outcomes and experiences over the duration of the trial.

1.5.7 Chapter 8 – Interpretation and Discussion

Chapter 8 provides an interpretation and discussion of the complete data set. The interpretation of the data draws upon the analysis presented in Chapters 5, 6 and 7. The chapter reveals key insights into the nature of the project experiences among the participants in the Pathways Home for Respiratory Illness project.

1.5.8 Chapter 9 - Conclusion

Chapter 9 outlines the conclusions of this research. A review of all major findings is discussed along with an outline for future work in this emergent research area.

1.6 Chapter One Reflections

This chapter has provided a summary of the background to the thesis and identified the research questions and objectives. It highlighted the contribution the investigation makes to the theory and practice of health informatics research in the area of

evaluation of patient-centred information and communication technology (ICT) tools within the home or community setting.

It has provided a background to the concerns that frame this research and outlines the conceptual framework within which the research was conducted. In this context, the research questions and research objectives, along with a discussion on the scope of the research to explore the influence of an online patient diary on the health outcomes and experiences of people with chronic obstructive pulmonary disease (COPD) participating in a mentored self-management clinical controlled trial.

This chapter outlined three levels of contributions the thesis provides to the knowledge and practice in health informatics research at a substantive, methodological and theoretical level. The chapter concluded by providing a summary review of the thesis structure outlining the remaining eight chapters.

In the next chapter (Chapter 2), provides a detailed description of the Pathways Home for Respiratory Illness Project within which the research was located. The quantitative measures of clinical outcomes, self-efficacy for self-management and quality of life survey instruments employed as evaluation techniques in the trial will be explained. Finally the development and implementation of the ICT support for the project is described.

Chapter 2 The Pathways Home for Respiratory Illness Project

> Patients – particularly those with chronic diseases – would benefit from improved health outcomes, better access to their own health information, and less complex interactions with providers across the healthcare sector (BCG, 2004, p. 6).

2.1 Introduction

This chapter provides a description of the Pathways Home for Respiratory Illness Project, within which this research was conducted. The chapter describes the Pathways Home for Respiratory Illness Project methodology, the IT tools developed to assist participants and mentors and the training provided.

- Section 2.2 provides a background to the Pathways Home for Respiratory Illness Project
- Section 2.3 briefly introduces chronic obstructive pulmonary disease.
- Section 2.4 summarises the aims of the Pathways Home for Respiratory Illness Project.
- Section 2.5 provides details of the approach taken to the project. This includes a discussion of the clinical, self-efficacy and quality of life measures used in the intervention and the baseline indicators for the symptom monitoring process.
- Section 2.6 briefly describes the information system and the considerations taken whilst developing the system.
- Section 2.7 provides details of the training provided to the users of the information system.
- Section 2.8 provides a reflection of this chapter and the processes involved in conceptualising the intervention and developing the supporting information systems.

2.2 Project Background

Pathways Home for Respiratory Illness is a collaborative project involving researchers from the University of Tasmania's School of Medicine, School of Nursing, and School of Information Systems. The project is supported by the Tasmanian Department of Health and Human Services and funded by the Commonwealth Department of Health and Ageing. The project commenced in January 2005 and concluded in June 2008. Funding for an extension of the project, to enrol participants in the community through general practices, was gained in 2007 and this project commenced in January 2008. That project (Pathways to Lung Health) is beyond the scope of this research and is not described here.

The Pathways Home for Respiratory Illness project focuses on middle-aged and elderly patients with COPD in southern Tasmania. COPD is the fifth leading cause of death worldwide and a significant cause of morbidity (WHO, 2006). In Australia,

COPD is identified as the third leading cause of burden of disease (Mathers et al., 2001) with sufferers experiencing multiple co-morbidities (GOLD, 2007).

2.3 Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is typically a combination of two lung diseases, emphysema and chronic bronchitis characterised by shortness of breath. This shortness of breath initially occurs with exertion but becomes progressively worse over time. It is a major cause of disability, morbidity and mortality, and is currently one of the leading causes of disease burden in Australia (AIHW, 2006a).

Most commonly COPD is caused by the gradual destruction of lung tissue due to smoking (NHS, 2004). This destruction of lung tissues makes the lungs floppy and less able to exchange oxygen and carbon dioxide (AIHW, 2006a). Patients with COPD frequently have a persistent cough, producing a small amount of sputum each day.

COPD is more prevalent among men in lower socio-economic groups. However, reflecting the increased popularity of smoking by women in the second half of the 20th century the rates of COPD for women are rising. It is anticipated that over the next 20 years death rates from COPD in women will overtake those in men (Bellamy & Booker, 2003; Hansen, Walters, & Wood Baker, 2007; McKenzie, Frith, Burdon, & Town, 2003).

There is no existing treatment that reverses the destruction of lung tissues underlying COPD. However, smoking cessation has been demonstrated to slow the progression of the disease over a long period. Also exercise-based rehabilitation programs have been used to improve the quality of life and exercise capacity of persons with COPD (AIHW, 2006a).

COPD is estimated to affect over 7,000 Tasmanians, with over 450 new cases being diagnosed each year (extrapolated from national figures) (NSW Health). Hospitalisation of people with COPD is often precipitated by an exacerbation requiring acute care support. These patients often have little or no contact with the acute care sector between exacerbations, with varying degrees of input from community health sectors and sporadic contact with specialists or general practitioners. Best practice indicates that seamless models of care across the acute care/community interface, incorporating education, rehabilitation and medical and self management are best suited to meet the dual requirements of improved outcomes for patients and a decrease in hospital bed days for this group of people. Supported early discharge and home based care of people with exacerbations of COPD have shown promising results with positive responses from patients, carers and health care providers and demonstrated savings made in the terms of cost (Barnett, 2004).

2.4 Project aims

This project aimed to assist people with COPD to achieve self-management skills, mediated through the development of self-efficacy for patient-identified health behaviours. Self-efficacy is a core construct of Social Cognitive Theory (Bandura, 1986), while awareness that individuals may vary in their motivation to enact behaviour change was informed by the Trans-theoretical Model of Change (Prochaska, DiClemente, & Norcross, 1992).

The project supported self-management through self-monitoring and recording of symptoms (preferably in an electronic format) with a graphical longitudinal feedback report provided to participants and their mentors.

2.5 Project Approach

During the initial phases of the project the methodology was developed. The first phase of the project consisted of the formation of a multidisciplinary team. The Pathways project team consists of clinicians and researchers drawn from a range of disciplines including respiratory medicine, nursing, physiotherapy and information systems. Team formation and the process of negotiating the relevant positions and roles within the team was undertaken during the project initiation phase. The navigation of power relations is an important factor in multidisciplinary team formation, particularly within the medical field (Atwal & Caldwell, 2005). This was confirmed by experiences during the early development stages.

An evidence-based review of the literature and an iterative process of discussion among the team culminated in the identification of a preferred methodology for the development of self-efficacy and self-management skills and a set of clinical indicators to be used to evaluate the effects of the controlled trial. Self-reported quality of life surveys were also used to measure changes in participants' perceived quality of life. These measures are detailed in sections 2.5.1 and 2.5.2 below.

2.5.1 Clinical Indicators

A range of clinical indicators, determined primarily by the respiratory physicians, were used. The clinical indicators were initially collected at enrolment, in hospital, with follow-up data collected at 3 monthly intervals in the participant's home. The clinical indicator data including the following:

2.5.1.1 Mini-Mental State Examination

Developed in the 1970s the Mini Mental State Examination (MMSE) is the most commonly used test for memory problems (Folstein, Folstein, & McHugh, 1975). The MMSE test is used to screen for the presence of cognitive impairment in the following areas:

- Orientation;
- Memory;
- Attention and Calculation; and
- Language, Writing and Drawing.

The MMSE is quick and simple to use and is based upon a series of questions and tests (see Appendix 1). Scoring is based on correctly answered questions. A maximum score of 30 points is possible. The scores indicate the areas of difficulty normally evident in a person presenting with cognitive problems such as memory, thinking, attention, reasoning, decision making and dealing with concepts.

- Scores of 27 and above are considered normal
- Scores of between 23 and 26 indicate a borderline condition

- Scores of 22 and below are abnormal

2.5.1.2 Weight

Weight is a significant indicator of health in people suffering from COPD (Andreassen & Vestbo, 2003). Unexplained weight loss is common in people with COPD (Schols et al., 1993). There is a well recognised association between body weight and an inverse relationship between body mass index (BMI) and survival in people with COPD has been reported in prospective survival studies (Gray-Donald, Gibbons, Shapiro, Macklem, & Martin, 1996; Schols, Slangen, Volovics, & Wouters, 1998; Wilson, Rogers, Wright, & Anthonisen, 1989). In addition, low BMI is now recognised as an independent risk factor for mortality in people with COPD, with the association being strongest for those with severe COPD (Landbo, Prescott, Lange, Vestbo, & Almdal, 1999).

Therefore, weight was recorded regularly for the participants in this trial. Weight was recorded by the research assistant, using the same scales, at each quarterly visit. Additionally, participants recorded their weight weekly using their home scales, as part of their symptom monitoring.

2.5.1.3 Spirometry

Spirometry is the most common of the range of pulmonary function tests used to measure lung function. It is used specifically to measure the volume and flow of air that an individual can inhale and exhale. Thus spirometry is an important tool used in assessing respiratory conditions such as COPD.

The following spirometry parameters were measured for each participant, both control and intervention, at enrolment and quarterly.

- Forced vital capacity (FVC) - The maximum volume of air, measured in litres that can be forcibly and rapidly exhaled.
- Forced expiratory volume (FEV1) - The volume of air expelled in the first second of a forced expiration.
- Forced expiratory volume/Forced vital capacity ratio (FEV1/FVC Ratio) - This is the ratio of FEV 1 to FVC. In healthy adults this should be approximately 75 - 80%.
- Forced Expiratory Flow 25-75% (FEF 25-75%) - This is the average flow of air coming out of the lung during the middle portion of the expiration.

In addition to the raw data the predicted and percent predicted FEV1, FVC and FEF 25-75% were also collected. The predicted values are based upon the expected values for patients of similar height, age, sex, race and weight. A value is usually considered abnormal if it is less than 80% of the predicted value for that person (Kaufman, 2006).

The spirometry scores were evaluated in relation to the Global Initiative for Chronic Obstructive Lung Disease scale (see Table 2.1).

Table 2.1: Spirometric Classification of COPD Severity

	Severity Based on Post-Bronchodilator FEV1
Stage I: Mild	FEV1/FVC < 0.70 FEV1 ≥80% predicted
Stage II: Moderate	FEV1/FVC < 0.70 50% ≤FEV1 < 80% predicted
Stage III: Severe	FEV1/FVC < 0.70 30% ≤FEV1 < 50% predicted
Stage IV: Very Severe	FEV1/FVC < 0.70 FEV1 ≤30% predicted OR FEV1 <50% predicted plus chronic respiratory failure

(GOLD, 2007, p. 3)

2.5.1.4 Dyspnoea

The participant's degree of dyspnoea (breathlessness) was measured using the modified Medical Research Council (MRC) dyspnoea scale. This measurement was undertaken at recruitment and repeated at quarterly intervals.

The Medical Research Council (MRC) dyspnoea scale actually measures perceived respiratory disability and has been in use for many years for grading the effect of breathlessness on daily activities (Fletcher, 1960). It is simple to administer and allows the participants to indicate the extent to which their breathlessness affects their mobility. (Bestall et al., 1999)

The MRC dyspnoea scale is a questionnaire that consists of five statements about perceived breathlessness as described in Table 2.2.

Table 2.2: MRC grading of functional limitation due to dyspnoea

Grade	Symptom complex
Grade 1	"I only get breathless with strenuous exercise"
Grade 2	"I get short of breath when hurrying on the level or up a slight hill"
Grade 3	"I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level"
Grade 4	"I stop for breath after walking 100 yards or after a few minutes on the level"
Grade 5	" I am too breathless to leave the house"

Adapted from (Soicher, Dutton, & Bourbeau, 2002, p. 348)

2.5.2 Self-reported Measures

A range of self-reported measures were employed to provide for the collection of data at quarterly intervals. The self-reported measures were validated survey instruments used to measure the participant's self-efficacy for self-management and quality of life outcomes. These measures and their frequency are described in detail in the following sections.

2.5.2.1 Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale

This 6-item questionnaire is a valid measure of self-efficacy in subjects with chronic disease. It covers several domains that are common across many chronic diseases and has an internal consistency reliability of 0.91. It has been validated in English speaking populations, and improved self-efficacy has been found to be associated with reduced healthcare utilisation in subjects with a range of chronic diseases (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

Items in the Stanford self-efficacy for managing chronic disease 6-item scale, here after referred to as Stanford Self-Efficacy, are measured on a scale of 1 to 10 with higher scores indicating higher self-efficacy. Each of the items in this scale measures self-efficacy for a specific activity.

- Item 1 measures the self-efficacy to manage the effects of fatigue caused by their disease to prevent them from limiting a person's activities.
- Item 2 measures self-efficacy to keep the physical discomfort they experience from limiting what they want to do.
- Item 3 measures self-efficacy to manage emotional distress so it does not interfere with things want to do.
- Item 4 measures the self-efficacy to limit other symptoms or health problems from affecting the things they want to do.
- Item 5 measures self-efficacy to reduce the number of doctor's visits required to manage the condition.
- Item 6 measures self-efficacy to undertake actions to reduce the amount their disease influences their everyday life, other than taking medications.

The final score is the mean of each of the above items and each holds equal weight in determining the final score. This questionnaire (see Appendix 2) was administered at enrolment and then every 3 months during the project.

2.5.2.2 SF36v2 Health Survey

The SF-36 Health Survey (SF36) has long been regarded as one of the world standards for patient-reported health outcomes assessment. The SF-36v2 Health Survey (SF36v2) is based on the SF36 and consists of a 36-item survey (see Appendix 3) that measures general health status. The SF-36v2 measures the following eight health related domains:

- Physical functioning;
- Role limitations due to physical health (role-physical);
- Bodily pain;
- General health perceptions;
- Vitality;
- Social functioning;
- Role limitations due to emotional problems (role-emotional); and

- Mental health.

The SF36v2 is a generic measure which takes only 5 to 10 minutes to complete and can be self-administered to persons ages 14 and older. (Jenkinson, Stewart-Brown, Petersen, & Paice, 1999).

The SF36v2 was administered at enrolment and then every 3 months during the project. Analysis of the SF36v2 is complex, if undertaken by hand, but can be undertaken using specific software purchased with the license to administer. The survey when scored provides a number of summary items, the physical component summary and the mental component summary are used within this research.

2.5.2.3 Hospital Anxiety and Depression Scale

The hospital anxiety and depression scale (HADS) was developed as a reliable self-assessment instrument for detecting depression and anxiety in patients seen in hospital medical outpatient clinics. These subscales have also been found to be valid measures of the severity of the emotional disorder (Zigmond & Snaith, 1983). It has been widely used to measure psychological distress in patients and is available in many languages. (Bjelland, Dahl, Tangen Haug, & Neckelmann, 2002).

The HADS survey contains 14 items measured on the two subscales of anxiety and depression. Each item is rated against a four-point scale. The maximum score against each subscale is 21. Scores of 11 or more on either subscale are considered to be indicative of a significant 'case' of psychological morbidity, while scores of 8–10 represents 'borderline' and 0–7 'normal' (Zigmond & Snaith, 1983). This questionnaire (see Appendix 4) was administered at enrolment and then every 3 months during the project.

2.5.3 Participant Recruitment

The participants were recruited while hospitalised with an acute exacerbation of their COPD and allocated to the intervention or control (usual care) group according to domicile. The randomisation was by domicile to decrease the risk that a control participant may be visited by a trained mentor, should they require care from a community health nurse (CHN).

The inclusion criteria for the participants were:

- Age over 45 years;
- Lives in catchment area – that is southern Tasmania;
- Formal diagnosis of COPD following the COPDX guidelines including spirometry;
- Has had one exacerbation of COPD in the last 12 months;
- Passes a cognitive assessment with a mini-mental state examination score >21;
- Able to provide informed consent;
- Has telephone;
- No diagnosis of other active lung disease; and
- Not undergoing palliative care.

2.5.4 Symptom Monitoring Diary

As part of the intervention the participants in the intervention arm undertook symptom monitoring. This was undertaken using a personalised symptom monitoring diary. The symptom monitoring diaries were completed daily and participants were asked to evaluate their COPD related symptoms each day against the predetermined normal baseline measures (see Section 2.5.4.1).

The daily diaries were provided in both paper and electronic formats (for examples see Appendix 5). All participants commenced the intervention using the paper diary and could progress to the online diary at their own pace, after an initial six week introductory period.

2.5.4.1 Baseline Symptom Measures

At recruitment participants were asked to identify their normal baseline levels of dyspnoea, cough, sputum and daily activity levels using self-administered questions. These baseline measures were then used as points for comparison by the participants when completing their daily diary.

The modified baseline dyspnea indexes (BDI), adapted from Mahler, Ward et al. (2004) (see Table 2.3) were used to determine individual baseline measures of dyspnoea.

Table 2.3: Grades and descriptors for each component of the BDI

Baseline dyspnea index	
Functional impairment	
NONE	I can perform usual activities without shortness of breath.
SLIGHT	I am short of breath in at least one activity, but have not completely stopped any activity.
MODERATE	I can't do at least one usual activity due to shortness of breath.
SEVERE	I can't do most or all activities due to shortness of breath.
VERY SEVERE	I can't do most or all activities and would be unable to work due to shortness of breath.
Magnitude of task	
NONE	I am short of breath only with extraordinary tasks, such as carrying very heavy loads on level ground, lighter loads uphill, or running. No shortness of breath with ordinary tasks.
SLIGHT	I am short of breath only with major tasks, such as walking up a steep hill, climbing one or more flights of stairs, or carrying a moderate load on level ground.
MODERATE	I am short of breath with average tasks, such as walking up a gradual hill, climbing less than one flight of stairs or carrying a light load on the level.
SEVERE	I am short of breath with light tasks, such as walking on level ground or standing.
VERY SEVERE	I am short of breath at rest, while sitting, or lying down.
Magnitude of effort	
NONE	I am short of breath only with the greatest imaginable effort.
SLIGHT	I am short of breath with extreme effort. I must pause only if the activity requires extreme effort.
MODERATE	I am short of breath with moderate effort. I need to pause and it takes longer to complete the task than the average person.
SEVERE	I am short of breath with little effort. I need to pause frequently and it takes at least 50 % longer to complete the task than the average person.
VERY SEVERE	I am short of breath with no effort.

(Mahler et al., 2004, p. 168)

Based upon Leidy et al. (2003) participants were asked to indicate the colour and volume of their daily sputum production and how difficult expectoration was using the indicators in Table 2.4.

Table 2.4: Sputum indicators.

	Colour	Sputum Volume	Difficulty in expectoration
None	no sputum	nil	unaware of any difficulty
Slight	mucoid, white or cream	1 teaspoon per day	rarely caused a problem
Moderate	Yellow	1 tablespoon per day	noticeable as a problem
Severe	Green	1 eggcup per day	caused a great deal of inconvenience
Very Severe	Brown	more than 1 eggcup per day	almost a constant problem

Based upon (Leidy, Rennard, Schmier, Jones, & Goldman, 2003).

Participants were asked to indicate the amount of time they spent each week on certain daily activities such as showering, cooking, collecting mail, housework, gardening or more formal exercise. Responses were recorded in relation to a typical week in the 4 weeks prior to them becoming unwell. These estimates were then averaged to provide a calculation of the average daily activity in minutes.

Finally the participants were asked to indicate their normal daily use of reliever medication when they were well.

All these indicators were then used as the normal scores for the individual participants and personalised diaries were generated based on these measures.

2.5.4.2 Additional diary questions

The symptom monitoring diary also asked participants to indicate their feeling of wellbeing on a daily basis and to indicate if they had had visits to or from different types of healthcare professionals (see Appendix 5 for full listing). A free text field was included for the participants to enter anything they considered to be important or unusual about their day to look for possible relationships.

2.5.4.3 Diary process

The diary was completed daily by the participants either in paper format, by circling the appropriate measure or online, by clicking the measure. The scales used were based upon a positive or negative scale of -3 to +3. Where -3 indicated much worse symptoms than normal (0) and +3 indicated much better symptoms than usual. The exception to this was the medication use where -3 indicated much less medication than normal (0) and +3 indicated much more medication than normal.

The longitudinal diary feedback provided a graphical representation of the daily diary based upon traffic lights. That is where any value was normal or better than normal the feedback colour was green, where the value was slightly worse than normal the feedback was yellow, for worse than normal orange and where the value was much worse than normal the feedback colour was red (an example is provided in Appendix 6). Included with the colour coded was the appropriate text. The feedback also provided the daily comments so that the participants could view a week of diaries and identify relationships.

For the paper diary the participants were supplied with sufficient personalised paper diaries for a three month period. Each paper diary contained a full week of questions. Once the diary was completed the participants mailed them to the research office, in prepaid envelopes, where they were entered into the database and a feedback sheet produced and mailed back to the participants. This process was resource intensive and could take between 3-7 days depending upon the postal service and when they were sent. Thus the information on the feedback sheets could be up to a fortnight old before it was received by the participants.

When using the online patient diary the diary was completed each day and only visible for that day. The feedback response was instantaneous with the past seven days of entries visible at the click of a button. The feedback received by each method was the same but the age of the data was different.

2.5.5 Mentoring

Community health nurses from four different practice settings, situated in both rural and urban areas of southern Tasmania volunteered to act as mentors in the trial. The mentors were prepared for their mentoring role by being trained in the Trans-theoretical Model of Change (TTMC) and motivational interviewing (MI), as well as in utilisation of the supporting information systems. The TTMC aims to develop effective interventions to promote health behaviour change, while MI is a directive, patient-centred counselling style which assists participants to change their behaviour while respecting their choices about the change (Britt, Blampied, & Hudson, 2003; Rollnick, Heather, & Bell, 1992; Rollnick & Miller, 1995).

Following discharge, intervention group participants were linked with a CHN mentor from the local community health centre, who acted in partnership with them to facilitate the development of self-management during their period of involvement in the study.

Mentors visited participants in their home on two occasions soon after their discharge from hospital to establish contact, initiate the rapport-building process, and to perform initial assessment of the situation and initial orientation of the participant to self-monitoring. They then maintained contact at regular intervals via the telephone, commencing with weekly contact and extending to monthly. The mentor encouraged the client to recognise adverse health behaviours and to formulate new health behaviours and structure these into written action plans. Progress against each action plan was monitored during the regular telephone contact and recorded in the database.

2.6 The Information System

The project was supported by an underpinning information system used to collect, store and retrieve the data from various sources: participants, mentors and research team. The next sections describe the challenges, specifications and considerations undertaken in the development of the information system.

2.6.1 The Challenges

From an information systems perspective, developing and deploying information systems to support self-efficacy and self-management amongst chronically ill participants presents numerous challenges. The COPD participants are older persons,

between the ages of 50 and 90 with minimal experience with information technology and many have other conditions that make manipulation and/or visualisation of small pieces of equipment difficult. These characteristics have implications for the technology and systems design and implementation.

Critically, the project team were keen to avoid the possibility that any ICT systems introduced might end up simply replacing participant dependency on health professionals with a dependency on the technology. This would result in participants undertaking the monitoring of their symptoms without actually developing the self-efficacy and self-management skills necessary to respond to changes in their illness. To this end the project team made considerable efforts to identify and accommodate the range of participant characteristics from amongst potential users of the system in the design, deployment, training and use of the information system developed. In essence, this involved providing a variety of different accessibility tools and the provision of an extensive range of data entry methods to enable accessibility for all members of the disease cohort.

Due to the multidisciplinary and patient-centred nature of the team many of the early decisions of project design and implementation were made solely by the team, with consideration of their combined experience being an important factor. However, as the participants have become more involved and experienced with the project and its processes there has been increasing ability and opportunity for them to have input. This is particularly emphasised in the area of the participant online patient diary interface and longitudinal data views, but is also evident in the fact that the participants initiate any change in technology use. That is, the participants commence the trial using paper based data collection methods and move to computers only when they initiate the change. This change can be facilitated by the CHN mentors, the research assistant at the time of the quarterly review or simply by the participant contacting the project team.

2.6.2 IT Considerations

The close involvement of the whole project team was integral to the complete project development cycle and resulted in a deep understanding of all aspects of the project and the intermingling of ideas from all disciplines involved in the project throughout the development cycle. Throughout the conceptualisation and specification processes the IS researchers were careful to encourage and support the team to identify their discipline specific requirements and those of the participants rather than limiting the requirements to those perceived to be technically less challenging. The major limitations resulted from budgetary constraints and the desire to develop the project with a view to support sustainability and future expansion to include other chronic illnesses. This resulted in the need to conform to the current specifications of local health department systems and intended state and national initiatives.

Using the expertise of the project team and initial brief interviews with COPD sufferers an understanding of the potential range of technological experience and expertise of this group was developed. The picture that emerged was that of a group of elderly people with little or no exposure to or trust of technology. All had telephones, a minimum recruitment requirement, with very few having mobile phones or computers.

The initial intention was to deploy a range of technologies including paper based data entry, telephone using a call centre through the use of interactive voice response (IVR) to full web-based data entry on desk-top PCs and via mobile devices (PDAs). As these groups frequently have limited financial resources all hardware requirements were provided by the project.

2.6.3 Technology Decisions

It was initially proposed that a range of technology options would be made available to the participants. As the project recruitment got underway and the mentors and project team had more experience dealing with people with COPD it became evident that these people would not utilise a full range of technologies, particularly in the earlier stages.

The elderly participants all stated at recruitment interviews that they did not use the telephone for banking or similar purposes and that they disliked IVR systems and would rather talk to a real person. Short Message Service (SMS) was also considered but the majority of the COPD participants are elderly, without mobile phones and have impaired eye-sight and or dexterity. These factors led to the decision that the only options developed would be paper or online patient diaries.

2.6.4 Functional Specifications

Determining the functional specifications was a time consuming process as this was the first time the clinical members of the research team had operated closely with IS researchers in the development of support tools. Some functionality was more easily determined and defines than others. For example the security requirements were evident and could be primarily determined by the IS development team. Security was ensured by storing data in a de-identified format on secure servers within the university firewalls. Online access was provided through password access to the site. Different levels of access were available dependent upon the user type. Participants could only access or enter their own data, mentors could only access or enter the data relating to their assigned participants, the research assistant had access to the forms required for data entry and the research team members had access to the relevant de-identified data for their research requirements.

The development for the participants was in part constrained by the participants themselves (see section 2.5.3) but was also limited by the trial requirement for a single intervention for participants. This led to the development of the online patient diary in isolation from the participants. Access to online participant forums and information sources were considered but it was determined that if present they had the potential to confound the trial outcome evaluation data. However, there was no limitation placed upon the usage of the computers once they were made available to the participants.

The development for the mentors surrounded supporting the mentoring processes. Thus online forms were developed to provide the mentors with the ability to enter data directly into the database at the time of the mentoring session, or after when convenient. The forms reflected the mentoring cycle of goal setting, action planning and progress reporting (see Appendix 7). Thus once the actual forms were determined the functional requirements were quite obvious. Attempts to involve the mentors in

the design of the web interface, using participatory design methods, was unsuccessful as they could not think about what they would require and at that time did not have a good grasp of the processes required within the intervention.

For the research team the determination of the requirements was quite challenging. The team spent many months determining the data to be collected. They had difficulty conceptualising the data structures required and although they understood the individual data elements they had difficulty determining the relationships between them. This process took five months to complete and considerably delayed the development. However, through this process the clinicians came to better understand the role and complexity of both the IS developers and information management.

2.6.5 Systems Design

There is a wide range of information systems development methodologies (ISDM) available for use (Avison & Fitzgerald, 1995; Checkland & Scholes, 1990; DeMarco, 1979; Hirschheim, Iivaari, & Klein, 1997; Iivari, 1994; Iivari, Hirschheim, & Klein, 2001; Keen & Scott Morton, 1978; Pava, 1986; Westrup, 1993; Wynekoop & Russo, 1993). Conventionally in the design of systems within multidisciplinary settings there is a range of techniques and approaches that can be used (Barnard & Grudin, 1988; Giaglis, 2001; Grudin, 1990; Iivari, Hirschheim, & Klein, 2001; Mayhew, 2001; Singh, Burke, Turner, & Castro, 2003). Numerous approaches to systems analysis and design recognise that involving users is an important aspect of system design and deployment.

When deciding upon the appropriate ISDM for this project account was taken of the experience of the project team and the IS development team and also the complexity of the environment into which the system was to be introduced. The actual system is moderately simple in its functioning but the environment is complex. From a technology perspective, this work is informed by theoretical insights drawn from a range of approaches that indicate that successful design and deployment of ICTs rely on understanding users needs and ensuring technology is both easy to use and useful (Singh, Burke, Turner, & Castro, 2003). It was clear that given the small multidisciplinary team with a relatively short timeline we needed to explore agile systems development techniques like extreme programming (XP) or feature driven development (FDD) (Augustine, Payne, Sencindiver, & Woodcock, 2005; Coad, Lefebvre, & De Luca, 2002; Erickson, Lyytinen, & Siau, 2005; Pryma, 2002; Syed-Abdullah, Holcombe, & Gheorge, 2006; Turk, France, & Rumpe, 2005) .

It was decided that the most appropriate methodologies would use feature driven development. This decision was based upon the fact that the development was not a highly complex technology system but what we did need to do was bring the team forward and within this context the idea of building feature sets rapidly, modelling appropriate relationships amongst team participants and stakeholders. This worked very well as a conduit for conceptually mapping the project out for the team.

2.7 Training of users

Each of the groups had different training requirements in relation to use of the system. Because the numbers involved were small and because all participants and mentors

were volunteers training was adjusted to their requirements. The different training requirements and methods are discussed below:

2.7.1 Participants

Participant education in self-management programmes remains a challenge. Due to the disease process, associated co-morbidities, ageing and underlying educational levels these difficulties are more pronounced in the COPD population (Nault, Dagenais, Perreault, & Borycki, 2002). Within this trial the participants had little or no experience with computing technology so an individualised, home based training programme was developed to facilitate the introduction of the online patient diary.

Each participant's experience of computers was evaluated prior to the installation of their computer to assist with the installation and tailoring individual training to participant needs. This evaluation occurred at the initial home visit, by the IS team, where the online patient diary was demonstrated to the participants and their ongoing interest was gauged. At this visit the home environment was also assessed and the most appropriate location for the computer was discussed with the participants. Following this visit an individualised training plan was determined based upon the participant's experience with computers and other technologies and also based upon the home support for the training. For each participant training was provided in their own homes. The training for many commenced with a basic demonstration and explanation of the various components and connections of the computer. This was followed by lessons in turning the computer on and off. Once the participants were comfortable with this they progressed to using the mouse. This was a major challenge for many of them because it was outside their experience. For those who found using the mouse a challenge the first lesson ceased here. They were asked to practice turning the computer on and using the mouse to play card games to improve their confidence with the mouse. All participants were followed up with a telephone call the day after the computer installation to see how they were progressing and to organise a follow-up visit.

At the second visit the participants were taught how to connect to the internet via the dial-up connection and introduced to the project website. Use of the online patient diary and the longitudinal feedback were also demonstrated. A full screen by screen user manual was provided for the participants to follow when undertaking diary entry (see Appendix 8). For those who had previous experience with computers and were confident with using a mouse the first two lessons were combined. Desktop shortcuts were provided to simplify the processes for the participants. The participants were then left to practice using the system with telephone support. Their activities were monitored online by the IS team and further training or support provided as required or requested.

2.7.2 Mentors

At the commencement of the project the mentors were surveyed to determine the extent of their experience with computers and to assess their perceived self-efficacy with computer use. Although all mentors had access to computers they had differing computer abilities and experiences, with 36.8% reporting that they using computers as little as possible and only 21.1% reporting to have generally had good experiences with computers. Each of the sites was provided with at least one notebook computer

to enhance the access and portability to the website[1]. In response to the low skill base, and after advice from the nursing researchers, it was decided that the mentors would be given access to paper forms initially. This made the process quite complex as forms were faxed into the research office and then manually entered into the database. This also made it more difficult for the mentors to fully engage with the system as they were able to avoid using it. A cut-off point was decided for the paper forms but this occurred 6 months after the trial commenced.

Initial training for the mentors was provided in small groups with demonstrations of the website, forms and also the participant feedback charts. The mentors were then provided with the opportunity for practicing during the small group sessions. A screen by screen user manual was provided for the mentors. Follow-up individual training sessions were provided for the mentors on request. A complete follow-up laboratory based retraining was undertaken after six-nine months for all mentors.

2.7.3 Project Team Members

Individual training was provided on request for the project team members. Minimal training was requested by this group but frequent support calls were received with some updating of skills required. All data cleansing and extraction was carried out by the IS research team.

2.8 Reflections

This chapter provided an overview of the Pathways Home for Respiratory Illness Project. This situates the current research, within the project intervention and has provided background information on the clinical trial outcome measures that will be analysed in Chapter 5. The chapter also provides information about the intervention processes and how the project and information systems were conceptualised and implemented.

The next chapter will provide a review of the key literature pertinent to the research domains.

[1] The challenges associated with the nurses' engagement with the technology are the subject of a paper currently being written.

Chapter 3 Literature Review

> Patients are the experts in their experience of a condition and coping with it. Capturing this experience and using it to benefit others as well as improve the quality of care is vital to improving the whole healthcare process. The development of e-health utilising the Internet could be pivotal in this regard (Detmer et al., 2003, p. 13).

3.1 Introduction

This chapter provides an insight into some of the core literature in relation to the key domain areas that are relevant to this research. It is structured in the following manner:

- Section 3.2 this section provides some background to the wider research setting. It provides some insights into the issues of healthcare system pressures in particular the increasing rates of chronic disease in our communities, changing models of care and the introduction of ICTs into healthcare.
- Section 3.3 provides a background to one solution that has been offered to the issues of increasing rates of chronic disease that of chronic disease self-management (CDSM). This section provides insights into core CDSM concepts and describes some of the programmes currently being used, with particular emphasis upon those in use in Australia.
- Section 3.4 gives some insights into the area of eHealth evaluation. This is a very broad area and so key literature and concepts are described in terms of two types of evaluation, summative and formative. This section concludes with a discussion of the difficulties of using formal evaluation techniques to evaluate the impact and experience of introducing eHealth applications into people's homes.
- Section 3.5 provides an investigation of some of the methods employed in evaluation of health outcome. There is a vast array of literature on the evaluation of health outcomes and so this section has been tailored to focus upon those more directly relevant to the current research.
- Section 3.6 concludes the chapter with reflections upon the literature presented and how this has framed and reframed the current research.

3.2 Background

This section provides some background to the broader discourses that exist around the research space. At the highest level there are three underlying core issues that shape this research environment and problem. Each of these issues will be briefly discussed in this section.

The health care system is complex and at all levels, and in all nations it is becoming more complex.

> You used to go to the doctor when you felt ill, to find out what was wrong with you and get some medicine that would make you better. These days you are as likely to be there because the doctor (or the nurse, the care coordinator,

> or even the computer) has sent for you. Your treatment will now be dictated by the evidence—but this may well be imprecise, equivocal, or conflicting. Your declared values and preferences may be used, formally or informally, in a shared management decision about your illness. The solution to your problem is unlikely to come in a bottle and may well involve a multidisciplinary team (Plsek & Greenhalgh, 2001, p. 625)

3.2.1 Healthcare System Issues

This section looks at cost and workforce issues that are affecting the health systems throughout the world.

Current health systems use a large proportion of gross domestic product (GDP) (between approximately 5-15% across the developed world) (Hitiris & Posnett, 1992; Parkin, McGuire, & Yule, 1987) and these costs are continuing to rise (Dormont, Grignon, & Huber, 2006). Whether on-going rises in the expense of health care are covered by the public or private sector, questions of on-going affordability are now a critical driver in initiatives aimed at health care reform. These cost increases are mainly related to changes in the nature of, and demand for care delivery and prescribed medicines as well as increasing costs associated with legislative compliance, litigation protection and medical insurances. Aligned to these are additional cost concerns over increases in the expense of administering health care systems(Armstrong, Gillespie, Leeder, Rubin, & Russell, 2007). These increases are variously attributed to growing system complexity contributing to growing inefficiency and bureaucracy as well as the prevalence of system waste, duplication of effort and abuse (Chau, Cummings, & Turner, 2004).

In Australia it is predicted that total health expenditure will increase from 9.4% of GDP in 2002–03 to 10.8% of GDP in 2032–33. This represents a total 15% increase over the projection period in the "health : GDP" ratio, or an annual growth of 0.5%. increases in population size and population ageing are expected to account for two-thirds of this growth (Begg, Vos, Goss, & Mann, 2008).

Current health care systems are finding it increasingly difficult to attract and retain suitably qualified clinical and carer staff across the range of services delivered (Armstrong, Gillespie, Leeder, Rubin, & Russell, 2007). This issue has been compounded by the expansion in the numbers of services and advances in the medical sciences that have led to increasing specialisation (Hughes, 1994). This in turn has made it difficult for existing health professionals, particularly in primary care to 'stay up-to-date' and contributed to the challenge of maintaining appropriate education and training. Alongside clinical autonomy, this partly accounts for the variability in expertise available across health care systems and variability in the different levels of care delivered. Significantly, most health professionals are facing increasing workloads and pressure to perform which has often contributed to low morale and problems of staff retention especially in regional or deprived areas (Bowman & Gross, 1986; Duckett, 2005; Dussault & Franceschini, 2006; Filmer, Hammer, & Princhett, 2002; Koblinsky, Campbell, & Heichelheim, 1999; Nigenda & Machado, 2000; Shields & Ward, 2001; Wibulpolprasert, 1999).

3.2.2 Increasing rates of chronic disease

Until the middle of the twentieth century infectious diseases and injury were the major causes of death or disability. Social, economic, scientific and healthcare changes have altered this and with these changes we have experienced increases in the prevalence of risk factors leading to chronic disease (Wagner et al., 2001). Many of these diseases are preventable but require significant investment in pubic and preventative health initiatives (Armstrong, Gillespie, Leeder, Rubin, & Russell, 2007; DoHA, 2006; Mansfield, 2003).

Nationally and internationally chronic diseases are a major health concern which places increasing burden on individuals, communities and health care systems. In terms of disability-adjusted life years, chronic illness currently accounts for over 70% of the burden of disease in Australia (Jordan & Osborne, 2007). This is expected to increase to 80% by 2020 (National Health Priority Action Council, 2006). Chronic diseases occupy the top ten causes of disease burden in Australia (Mathers, Vos, & Stevenson, 1999).

In 2001 $11 billion, more that one fifth of all health system expenditure in Australia, was used for management of chronic disease (AIHW, 2006b). More recently the Australian Federal government 2006–07 federal budget allocated $515million over 5 years for activation of patient self-management activities (Jordan & Osborne, 2007).

In the USA it is reported that chronic health conditions cost over $1 trillion a year, and this cost is likely to rise significantly in the future (DeVol et al., 2007).

Although many definitions of chronic disease exclude communicable diseases, in Australia, the National Chronic Disease Strategy (DoHA, 2006) argues that chronic disease occurs across the whole spectrum of illness, mental health problems and injuries, and that both communicable and non-communicable diseases can become chronic. Thus the National Chronic Disease Strategy supports the Australian Institute of Health and Welfare (AIHW, 2006b) definition of chronic diseases.

Chronic Diseases:

- have complex and multiple causes;
- usually have a gradual onset, although they can have sudden onset and acute stages;
- occur across the life cycle, although they become more prevalent with older age;
- can compromise quality of life through physical limitations and disability;
- are long term and persistent, leading to a gradual deterioration of health; and
- while usually not immediately life threatening, they are the most common and leading cause of premature mortality.

However, it must be recognised that people with chronic illnesses often normalise their condition and so they can manage the individual burden of the illness. Thus, health, chronic illness and disability are not mutually exclusive concepts or experiences when viewed from a patient's perspective. Individuals tend to normalise by redefining their perception of their health status to incorporate their condition. This

creates some complexity when it comes to defining the problem and outcomes of treatment (Anderson & Bury, 1988).

With the rapidly increasing incidence of chronic illness in all nations a number of chronic disease self-management (CDSM) programmes have been established. These programmes aim to explore methods to reduce health system crises and improve health outcomes for some categories of patients with chronic illness (Commonwealth of Australia, 2001a, 2001b). Common CDSM programmes will be discussed in greater detail in Section 1.3.

3.2.3 Changing models of care

The physician-patient relationship in traditional healthcare models involve the doctor acting as the sole source of expertise and decision making authority (Charles, Gafni, & Whelan, 1997). More recent alternative models include collaborative management (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997), patient empowerment (Funnell et al., 1991), shared decision making (Charles, Gafni, & Whelan, 1997), the partnership model (Holman & Lorig, 2000), and the chronic care model (Figure 1) (Wagner, 1998; Wagner et al., 2001). All decry the same concept that patient, physician, and family members should share information and make choices together (Barrett, 2005). Underlying this focus on collaboration are the premises that patients have the right to take part in all health decisions (Charles, Gafni, & Whelan, 1997), and that they are capable, with the right support, of making valuable contributions to these decisions (Wagner et al., 2001).

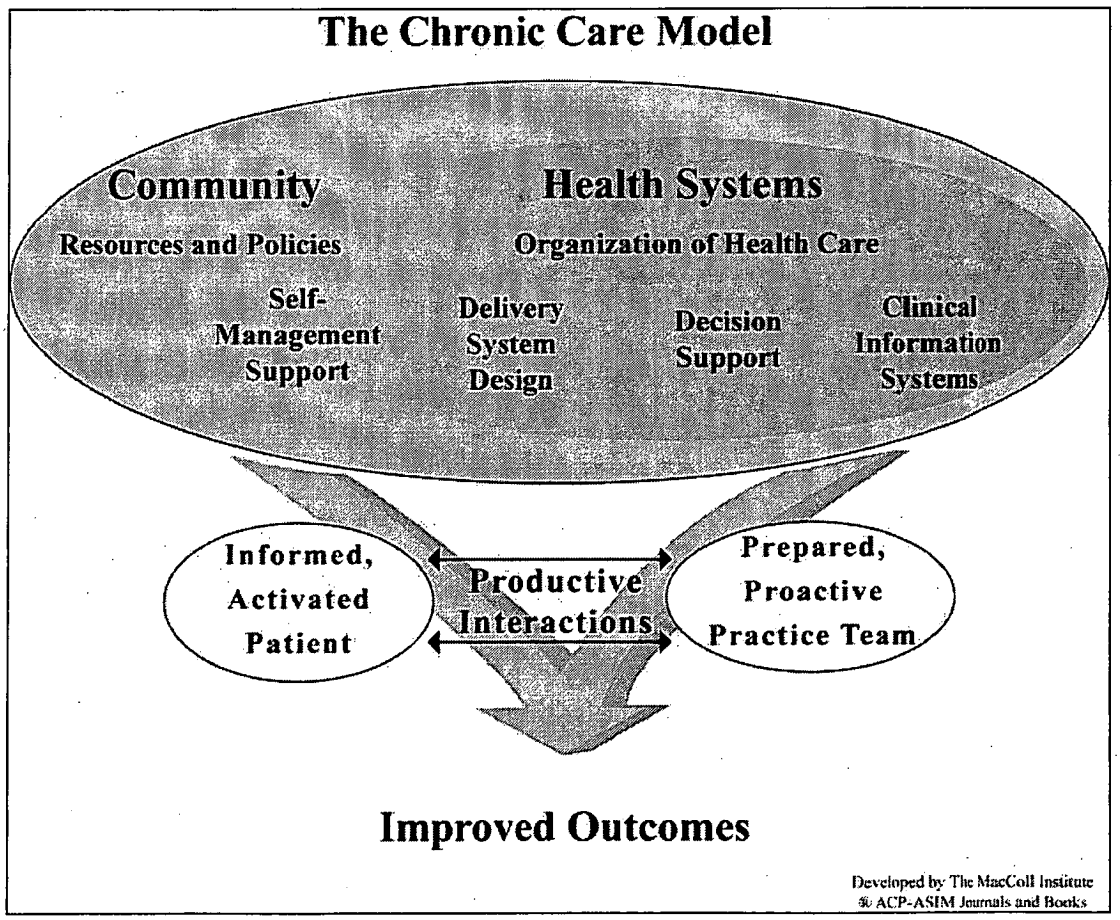

Figure 3.1: The Chronic Care Model

The chronic care model focuses on "linking informed, active people with chronic conditions with pro-active teams of health professionals" (DHHS, 2008). It recognises that the majority of chronic care does not take place in formal healthcare settings and recognises six key elements required to improve chronic care. They are:

- Community resources;
- The healthcare system;
- Patient self-management;
- Decision support;
- Delivery system redesign; and
- Clinical information systems.

There is now widespread recognition that there are a number of problems in terms of the delivery and quality of patient care. These problems are often summarised in the literature as 'overuse of approaches that cannot help, under-use of approaches that can help and/or misuse through errors in care' (Berwick, 1998; Bodenheimer, 1999) and have been the focus of a variety of approaches that claim to have solutions to improve quality of care defined as safe, effective, timely and patient-centred (Chau, Cummings, & Turner, 2004; JPS Health Network, 2004).

Grol (2001) identified a number of approaches that represent different perspectives of methods for improving care. "Some approaches focus on professionals, and others on organisations; some emphasize the value of self-regulation, and others believe in external control; some prefer a bottom-up method, and others a top-down method" (Grol, 2001, p. 2578). These approaches and their underlying assumptions are presented in Figure 3.2.

Approach	Assumptions
Evidence-based medicine Clinical practice guidelines Decision aids	Provision of best evidence and convincing information leads to optimal decision making and optimal care
Professional education and development Self-regulation Recertification	Bottom-up learning based on experiences in practice and individual learning needs leads to performance change
Assessment and accountability Feedback Accreditation Public reporting	Providing feedback on performance relative to peers, and public reporting of performance data, motivate change in practice routines
Patient-centered care Patient involvement Shared decision making	Patient autonomy and control over disease and care processes lead to better care and outcomes
Total quality management and continuous quality improvement Restructuring processes Quality systems Breakthrough projects	Improving care comes from changing the systems, not from changes in individuals

Figure 3.2: Approaches to Quality Improvement (Grol, 2001, p. 2579).

While there are a variety of perspectives on the nature of the problems being faced in health care and differences in terms of what the priorities, best solutions and best mechanisms are to address these problems, there is, at least at the broadest level some commonality amongst visions for the future of health care systems. Most visions of

the future recognise the need for health care systems to become more efficient, safer, knowledge-based, patient-centred, system minded and to provide universal, accessible and affordable care (Berwick, 2004)

Putting the patient at the centre of care and ensuring they are better informed is also seen as a method for improving quality of care by ensuring their involvement and giving them greater control (Grol, 2001). It is however based on the potentially problematic assumptions that patients are willing and able to take on these new responsibilities and that when they do it will lead to improved quality of care. To date, evidence on the impact of attempts to 'empower' patients on actual care practice and outcomes remains limited (Chau, Cummings, & Turner, 2004). It also remains unclear whether the impact of the availability of clinical information through sources like the Internet is wholly positive in terms of patient-doctor relationships (Nwosu & Cox, 2000). Clearly there is considerable development required before the implications of this approach for interactions between patients and clinicians can be optimised in terms of improvements in quality of care. There is however, a clear role for patient empowerment linked to the growing development of self-managed care and utilisation of alternative medicines (Cummings, Chau, & Turner, 2008). The area of chronic disease self-management programmes will be expanded upon in section 1.3.

3.2.4 Introduction of ICTs to health

In an era when health care systems in Australia and across the developed world are under increasing pressure to enhance the efficiency and effectiveness of their services to increasing numbers of patients at a time when available resources are limited, it is perhaps not surprising that health reform has been a major item on policy agendas. In an Australian context, alongside changes to Medicare, health care funding arrangements, medical insurances and the legal and regulatory environment, e-health initiatives have been identified as major drivers for overcoming the crisis in health care. The vision of the Australian National Health Information Management Advisory Committee through the introduction is:

> Health services and health sector management will be transformed in the years ahead by better use of information, re-engineered health services, and the cost effective use of information and communication technologies throughout the sector (NHIMAC, 2001)

Despite these challenges Australian governments at Federal and State & Territory levels as well as private sector providers have variously initiated programs to support the deployment of information and communication technologies. By opening up opportunities for increased information access, cost effectiveness, improved information delivery, update and evaluation the economic case for more ICTs is strong. However, this deployment also raises a number of clinical, socio-technical and legal challenges that have become increasingly evident as the implementation of more sophisticated ICTs solutions have met with mixed success.

The 2004 report by the Boston Consulting Group (BCG, 2004), conducted for the National Health Information Group (NHIG) and Australian Health Information Council (AHIC), summarises the benefits anticipated through 'better connected health systems' including:

- "Providers could make better informed clinical decisions more efficiently, adverse events would be reduced and unnecessary procedures could be avoided;
- Administrators could make more efficient and effective use of resources;
- Researchers could more effectively analyse disease pathways and the effectiveness of various interventions to help inform health policy and practice;
- Policy makers and funding bodies could more effectively direct their funding towards interventions that produce the most effective health outcomes; and,
- Patients – particularly those with chronic diseases – would benefit from improved health outcomes, better access to their own health information, and less complex interactions with providers across the health care sector" (BCG, 2004, p. 6)

The report acknowledges that the lack of a coordinated national approach to the provision and development of a common infrastructure, standards and to privacy, security and patient records as well as low levels of IT literacy in the health workforce continue to impede progress to the realisation of an interoperable health care.

However, whilst the BCG report presents arguments around strategies to ensure the deployment of ICTs in health care it fails to question the underlying assumption that benefits will accrue if the obstacles to the roll out of ICTs are overcome. This assumption is in part linked to the fact that much of the existing research literature in health informatics continues to report positive outcomes from the introduction of ICTs into health, whilst literature on 'failures' is poorly represented. In addition much of it may not be as valid and reliable as has previously been claimed and/or many of the measures of success reported have little to do with improvements in patient outcomes or care (Friedman & Wyatt, 2000; Moehr, Analin, Schaafsma, Pantazi, & Grimm, 2006; Wyatt, 2004). Additionally, the assumption is partly linked to a desire to consider health to be the same as any other sector and therefore to anticipate benefits on the basis of experiences with ICTs in other sectors.

This is inappropriate because as Leonard Schaeffer has recently pointed out 'unlike other sectors, the adoption of IT in health generally does not involve labour substitution or the replacement of existing systems but tends rather to lead to increases in labour to run the new system and the continued maintenance of the old' (Kaisernetwork, 2004). Aligned to this is the recognition that even where there has been a high level of technology adoption this is not an indication of actual use or changed work-flow practices (Chau, Cummings, & Turner, 2004). Indeed, given the 'productivity paradox' evident from analysis of longitudinal investments in ICTs across the economy as a whole (Willcocks & Lester, 1999) there is even a need to consider the possibility that e-health may not deliver on the vast predicted benefits.

The initial implementations of eHealth systems were primarily financial and administrative level systems which were previously designed and implemented in other sectors. This development was followed by the development of individualised systems that fulfilled specific functions for their unit. These implementations fulfilled the objectives of that unit but failed to exchange data with other parts of the service and have resulted in multiple legacy systems throughout hospitals, many of which now require replacement or integration into core systems (Burns, 1998).

The last two decades has seen the focus move from departmental or ward-based systems to large institutional based systems and further towards regional and national systems, particularly electronic health records (Haux, 2006a, 2006b). These have been further supported through the development of clinical applications specific to specialised settings. These include such systems as picture archiving and communication systems (PACS) for storing medical images and decision support and prescribing tools to support patient management.

There has also been recognition of the importance of improved communication between the acute care sector and the primary care sector. This understanding is based upon the realisation that information exchange is essential to enhance both the continuity of care and to facilitate multidisciplinary care of patients.

Whilst these changes have been occurring there has been a parallel development of a vast array of new and portable wireless technologies. These include personal computers and laptops, mobile telephony, wireless networks and personal digital assistants. Along side and making use of these developments has come the push towards patient-centred and home-based care. The driving forces behind the development of many eHealth applications are the increase in patient empowerment and the need for altered models of care particularly for people with chronic conditions (Koch, 2006).

The Internet provides the population with the ability to rapidly obtain health information in a private, anonymous and convenient environment (Fox & Rainie, 2000). The aim is that people can become actively involved in their care (Zeng & Parmanto, 2004). There is a wide range of online health tools available for accessing and use. Online resources can be controlled or uncontrolled and mechanisms are not necessarily in place to provide the population with the ability to categorise or recognise the validity of the content (Al-Busaidi, Gray, & Fiddian, 2006). Although these resources may improve patient knowledge, their effect on objective clinical outcomes is not consistent (Bussey-Smith & Rossen, 2007; Välimäki, Nenonen, Koivunen, & Suhonen, 2007). These Internet resources are outside the scope of the current research.

However, it is important to be realistic about the capacity of the population to embrace eHealth technologies. A recent Australian survey of household use of information technology found that 73% of all Australian homes had computer access and that 67% of all Australian households had home Internet access (ABS, 2007, p. 11). However, 77% of Australians aged over 64 years did not use the Internet from any site. Furthermore, 58% of people in the lowest income quintile and 40% of people with Year 12 or below education did not access the Internet from any location (ABS, 2007, p. 21). Similar Internet use rates have been recorded in other countries, with 24% of the population of the USA having no direct or indirect access to the Internet (Lenhart et al., 2003). There are also growing numbers of previous Internet users who had dropped out. This trend to stop using the Internet has been noted also in Europe (Wyatt, Thomas, & Terranova, 2002). The populations with little or no access to the Internet tend to be those most susceptible to chronic illnesses and less able to benefit from many eHealth initiatives.

The next section will define CDSM and provide insights into the core concepts underlying CDSM. It will then describe some of the larger CDSM programmes currently being used in Australia and other countries.

3.3 Chronic Disease Self-Management

With the worldwide increase in chronic diseases there is an increased interest in methods for the most appropriate and efficacious management of these diseases. Thus many countries, including Australia, are investing in chronic disease self-management programmes.

3.3.1 Defining self-management

Gruman and Von Korff (1996) proposed the following definition. Self-management:

> Involves [the person with the chronic disease] engaging in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes. (p.1)

It is important to recognise that the elements contained in this definition are about the behaviours of the patient. They are not models of self-management for health care systems, service providers or health professionals. However, there is some suggestion that the definition requires further elaboration.

Self-management "refers to a patient's ability to understand their condition and to manage and organise their access to key elements of their care. A patient who understands their illness, how to recognise early warning signs and take appropriate action, how to manage their lifestyle for optimal health outcomes and how to work effectively with health care providers and carers is seen to be a good self-manger of their condition" (Harvey, Battersby, & Misan, 2003, p. 3).

Self-management does not mean patients managing their conditions in isolation. The principle of self-management is to enable patients to know what services to access, how and when so they can maximise their own wellbeing. This requires an effective partnership between patient, carer and health service provider. Working together to ensure that essential care requirements are available when needed and that the various people involved in the care are informed the care and work together to ensure the best possible outcomes for patients (Harvey, Battersby, & Misan, 2003).

Partnership between patients and clinicians is an extremely important element of self-management. As suggested by Butler, Rollnick and Stott (1996):

> Patients and clinicians are both considered experts on the patients' problems; the consultation is, therefore, a meeting between experts in which the experiential expert (the patient) meets with the clarification expert (the physician). In this view, the object of the consultation is not to convert the patient to the physician's point of view, but to enlist the patient as a therapeutic ally and to negotiate mutually acceptable plans for enhancing the patient's wellbeing. (p. 1358)

Cameron-Tucker (2008) has synthesised acknowledged literature on self-management programmes (Battersby, Ask, Reece, & Marwick, 2003; Clark, Becker, Lorig, Rakowski, & Anderson, 1991; Corbin & Strauss, 1988; Kralik, Koch, Price, & Howard, 2004; Lorig, 2003) to develop the following comprehensive definition of self-management:

> Self-management is a dynamic process incorporating an individual's capability and confidence to be self-reliant in undertaking responsibilities and engaging in activities, such as adopting health-related behaviours, in a self-

> tailoring context to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and medical, emotional and social domains. In order to retain an acceptable and meaningful quality of life, such management involves the capability to undertake core tasks or responsibilities (Cameron-Tucker, 2008, p. 365).

3.3.2 Chronic Disease Self-Management Theoretical Basis

Given the burden of chronic disease in Australia and the shift in health policy towards patient-centred care the focus on self-management is not surprising. Through the National Chronic Disease Strategy, National Service Improvement Framework and the Blueprint for Chronic Disease Surveillance (Commonwealth of Australia, 2006) the Australian Government has initiated a major focus on chronic disease. It is evident that, self-management has risen to prominence at the policy level through the National Chronic Disease Strategy (Jordan & Osborne, 2007).

Evidence suggests, that patients make better use of health care professionals' time and have enhanced self-care when they have effective self-management skills (Barlow, Turner, & Wright, 2000; Lorig et al., 1999). Systematic reviews indicate clear clinical benefits for patients with conditions such as diabetes and hypertension through self-management programmes. However, such reviews are limited by the heterogeneity of interventions and outcomes (Chodosh et al., 2005; Warsi, LaValley, Wang, Avorn, & Solomon, 2003; Warsi, Wang, LaValley, & Avorn, 2004).

To assist patients to engage in self-care, Governments have begun to focus on formal self-management education programs. In 2005 the Australian Government assigned $36.2 million for the Sharing Health Care Initiative to explore the suitability of a range of education interventions (Australian Government Department of Health and Ageing, 2005).

There are a number of key theories from the health and psychology literature that predict and explain self-management attitudes and behaviours for people with chronic illnesses and are key to the successful development and implementation of CDSM programmes. These include:

3.3.2.1 Stages of Change Model

The 'stages of change model' or the 'trans-theoretical model of change' is a model of behaviour change that has been applied to chronic condition self-management (DiClemente & Velasquez, 2002; Ruggiero & Prochaska, 1993). This model is based on research undertaken by Prochaska and DiClemente into how people change their behaviour (Prochaska & DiClemente, 1983). Change can be undertaken either within an intervention program or on their own. Through this research they infer that the acquisition of health promoting behaviours and the cessation of risk behaviours involves the progression through five stages of change (DiClemente & Prochaska, 1998). The stages of change are: pre-contemplation, contemplation, preparation, action and maintenance (Shinitzky & Kub, 2001) relapse can occur at any point and can be considered another stage of change.

3.3.2.2 Social Learning Theory or Social Cognitive Theory

During the 1970s, whilst working in the field of aggressive behaviour, Albert Bandura developed the Social Learning Theory (SLT). The theory is based upon the

observation that people are capable of acquiring a significant amount of information merely by watching other people (Bandura, 1977). SLT has become better known as Social Cognitive Theory. It is a comprehensive theory of human personality and behaviour. These theories are widely supported in the field of psychology, and the influence in the health field is significant.

Von Korff et al. (1997) consider that effective self-management programs should be theoretically underpinned by social learning and behavioural theories. As applied to chronic disease self-management the relevant key principles of these theories are:

- Disease management skills are learned and behaviour is self-directed;
- Motivation and confidence (including self-efficacy) in managing one's condition dictate an individual's success;
- The social environment (i.e. family, workplace and health care system) support or impede self-management; and
- Monitoring and responding to changes in disease state, symptoms, emotions and functioning improve adaptation to the chronic condition.

3.3.2.3 Self-efficacy

The term self-efficacy refers to the belief in one's capacity to organise and execute the action needed to produce a given result (Bandura, 1997). Under certain circumstances and for specific conditions self-efficacy can enable the patient to become an expert patient (Ajzen, 1985; Bandura, 1982; Cummings & Turner, 2006).

Self-efficacy can be defined as follows: "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes" (Bandura, 1994: 71). The expectation that one can successfully complete a behaviour, or self-efficacy, is theorised to be an important predictor of whether one attempts the behaviour.

3.3.2.4 Health literacy

If people are to assume more responsibility for their health a degree of health literacy is essential. Health literacy has been defined as the 'degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (Nielsen-Bohlman, Panzer, & Kindig, 2004). Health literacy has been shown to be associated with health-relevant knowledge, improved skills, and health outcomes and lower health care costs (Nielsen-Bohlman, Panzer, & Kindig, 2004; Sihota & Lennard, 2004).

Patients' knowledge of their diseases, including causes, course and consequences, influences how they cope with them (Leventhal et al., 1997). However, health literacy impacts upon patient's ability to gaining knowledge of their disease. The recent international Adult Literacy and Life Skills Survey (ALLS) demonstrated that Australia has similar literacy levels to Canada. In the last decade there has been an increase in document literacy skills for recent migrants whose first language was not English. There remain inequities is literacy levels with those from lower economic

groups having lower literacy levels (ABS, 2006). Similarly in the UK, low literacy skills are associated with socio-economic deprivation and long-standing illness or disability (Sihota & Lennard, 2004)

Because of lower literacy levels, health literacy efforts may need to be targeted at those in the lower socio-economic groups. So with these lower literacy levels in the groups where chronic illness, and specifically COPD, is more prevalent, patient education remains a challenge. (Nault, Dagenais, Perreault, & Borycki, 2002).

3.3.3 Effective Self-Management Programs

Based upon a major literature review of over 400 articles, Wagner et al. (1996) developed a general model for successful self-management interventions. The model includes the following four essential elements:

- Collaborative problem definition;
- Targeting, goal-setting and planning;
- Self-management training and support services; and
- Active and sustained follow-up.

Essentially these elements will ensure the development of programmes that enable the patient to define their problems in conjunction with their health professionals. The issues that are of greatest importance to the patient and clinician should be the target of these programmes and provide for the setting of realistic goals and the development of personalised care plans. To produce success it is essential that the process is guided by the patient's readiness to change and the development of their self-efficacy skills. Programmes which include elements of instruction about disease management, behavioural support, and physical activity and also include interventions that address the emotional demands of having a chronic condition are more readily accepted and more successfully implemented. Additionally evidence demonstrates that reliable, clinician initiated, follow-up at regular intervals leads to better outcomes (Wagner, 1998; Wagner, Austin, & Von Korff, 1996).

There are a number of specific interventions that have been identified as increasing the effectiveness of chronic disease self-management programmes. These interventions include: symptom action plans, monitoring diaries, provision of information and partnerships between patients and clinicians (Gibson et al., 1998; Lorig et al., 1999; Mullen, Laville, Biddle, & Lorig, 1987). Each of these is discussed below.

3.3.3.1 Action Plans

> The action plan is the central point of management or partnering. All components of self-management solidify with use of a written action plan, including educational efforts, individualised drug therapy, and team communication with a unified approach. The plan must be clear, concise, and written in terms that the patient understands. It should be written from the patient's perspective, incorporating his goals and resources (Patel, Axen, Bartling, & Guarderas, 1997, p. 753).

International guidelines for disease management widely recommend the use of action plans (Jones, Pill, & Adams, 2000). Their efficacy is supported through abundant

research, including many randomised controlled trials (D'Souza et al., 1994; Gruman & Von Korff, 1996). Although many action plans are based upon objective monitoring those based upon subjective symptom monitoring have also been found to be effective (Charlton, Charlton, Broomfield, & Mullee, 1990)

3.3.3.2 Monitoring diary

Monitoring diaries are widely recommended to encourage self-management practices and play an important part as the process of completing them can aid in clarifying when, how much, and in what context the symptoms occur. However, symptom monitoring in isolation is rarely an effective method for managing symptoms (Blanchard et al., 1990a; Blanchard et al., 1990b; Greene & Blanchard, 1994).

Symptom monitoring diaries are best used in conjunction with action plans rather than treated as independent interventions. When used in combination these interventions have the ability to increase self-management behaviours, in particular the initiation of preventative actions (Clark, Evans, Zimmerman, Levison, & Mellins, 1994).

3.3.3.3 Information provision

Many consumers have access to a vast array of health information provided through a wide range of media such as pamphlets, books, magazines, video, CD-ROMs and the Internet. However, evaluating this information is proving to be difficult for many people and tailored information has proven to be the most useful (Anderson, Fitzgerald, Gruppen, Funnell, & Oh, 2003; Anderson, Funnell, Fitzgerald, & Marrero, 2000; Shepperd, Charnock, & Gann, 1999). The importance of health literacy was discussed in section 3.3.2.4 above. Eysenbach (2000) recognised the need for informed professionals who can assist patients in information seeking and decision making. Coulter, Entwistle and Gilbert (1999) recognised that patients prefer to be actively engaged with the health information supplied to them.

3.3.3.4 Partnership

Partnership is a core to CDSM. As previously stated CDSM is about collaborative working between communities of care and not about patients caring for themselves. Self-management is not an alternative to medical care but is an adjunct to it (Butler, Rollnick, & Stott, 1996; Cameron-Tucker, 2008; Cummings & Turner, 2005; Funnell & Anderson, 2004; Gallant, 2003; Harvey, Battersby, & Misan, 2003; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

Within CDSM there is an acknowledgement that both patients and clinicians are experts in relation to the chronic illness and each can bring a different, but not conflicting, perspective and set of experiences (Anderson & Bury, 1988; Bodenheimer, Wagner, & Grumbach, 2002; Butler, Rollnick, & Stott, 1996; Lorig, Holman, & Sobel, 1994; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

3.3.4 Current CDSM programmes in Australia

There are a large number of CDSM programmes being undertaken at national, state and local levels in Australia.

3.3.4.1 Stanford Chronic Disease Self-Management Program

Developed by Lorig and the team at Stanford University, the Stanford Chronic Disease Self-Management Program (CDSMP) is a group based workshop programme for people with different chronic health problems attend together. The programme consists of six workshops of two and a half hours duration, held weekly. Each workshop is facilitated by two trainers who have been trained as CDSMP leaders. The leaders usually include one non- healthcare professional with a chronic illness. Although initially developed for people with arthritis this programme has become the basis for may other programmes. It has now been used in the management of diabetes, HIV and AIDS and back pain. It has been developed and testing in both English and Spanish (Lorig, 2003; Lorig & Holman, 2003; Lorig et al., 2001; Lorig, Ritter, Villa, & Piette, 2008; Lorig et al., 1999; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). Further, the CDSMP Leader's Manual is also now available in Arabic, Bengali, Chinese, Dutch, German, Hindi, Italian, Japanese, Korean, Norwegian, Somali, Turkish, Vietnamese and Welsh.

3.3.4.2 Flinders Partners in Health

The Flinders Partners in health model was developed by the Flinders Human Behaviour & Health Research Unit (FHBHRU). It consists of a set of generic tools and processes that facilitate a structured process for assessment of self-management behaviours. This includes tools that encourage the collaborative identification of problems and goal setting which in turn lead to the development of individualised care plans. The generic tools include the Partners in Health Scale, Cue and Response Interview and Problem and Goals assessment (Battersby, Ask, Reece, Markwick, & Collins, 2003).

3.3.4.3 Heart Manual

The Heart Manual is a cardiac rehabilitation course for people recovering from acute myocardial infarctions, which can be either home or hospital based. The Heart Manual has been shown to be clinically effective in repeated studies (Lewin, Robertson, Cay, Irving, & Campbell, 1992). The Heart Manual programme has four components: the Heart Manual Facilitator training; Heart Manual facilitation; The Heart Manual book; and Audiotapes. This programme uses goals setting and action planning with encouraged exercise. The facilitators primarily contact patients using the telephone.

3.3.4.4 The Good Life Club

The Good Life Club project was a demonstration project under the Sharing Health Care initiative (Chronic Disease Self-Management). It was aimed at supporting multi-cultural clients, over the age of 50, living in the eastern suburbs of Melbourne who had diabetes with cardio-vascular disease co-morbidities in the development of self-management skills. The programme was based on telephone coaching to assist people with setting and reaching personal goals and to promote self-management. In addition participants were encouraged to work with their GPs to develop multi-disciplinary care plans. This programme utilised the trans-theoretical model of change as the theory underpinning it (Kelly, Menzies, & Taylor, 2003).

3.3.4.5 COACH

The COACH Program was developed by Vale and associates (Vale et al., 2003) and is a health professional based coaching for people with coronary heart disease. It trains people to "aggressively pursue the target levels for their particular coronary risk factors while working in partnership with their own physician(s)" (Vale et al., 2003, p. 2776). This programme uses hospital based coaches and employs both telephone and postal services to provide regular coaching sessions to patients. Coaching is based around teaching the patients to understand their risk factors and the levels of risk. They then assign target level for their risk factors and plan how to achieve these through regular clinician contact, lifestyle measures and medications.

3.3.4.6 Online CDSM

The Stanford team has been delivering a number of Internet based self-management programmes since 1998. They have undertaken a number of RCTs using online self-management support. The initial online programme was focussed on back pain education and consisted of a moderated discussion group (Lorig et al., 2002).

This programme was email based with email groups moderated by a physician, physiotherapist, psychologist, and two health educators. All discussions were initiated by the participants and the moderators did not restrict discussion. Results of this programme were very positive with improvement in disability in 69% of the email group after one year.

Another Internet based Stanford programme is The Healthier Living With Ongoing Health Problems Program. This is a version of the CDSMP for the Internet which provides similar content and structure to the original programme with online workshops being taken by group members (Lorig, Ritter, Laurent, & Plant, 2006). Disease specific tailored programmes have also been developed and trialled by the Stanford team.

The potential for benefit from these online CDSM programmes and the positive results need to be considered in light of the fact that access to these online resources is limited to people with computers and Internet access (section 3.2.4).

3.4 eHealth Evaluation

This section provides an overview of some concepts and methodologies employed in attempts to understand the influence of eHealth. Essentially there are a number of core information systems (IS) models and methodologies that were initially employed in evaluating eHealth, a number of which continue to be used. However, the inappropriateness of some of these methods has become more evident as more and broader applications of eHealth occur. Thus new methods of investigation are beginning to emerge. This section will commence by defining eHealth and will then provide some examples of a range of summative methods that have been employed in eHealth before investigating a number of recent formative methods currently being used to understand eHealth applications throughout the development lifecycle.

3.4.1 What is eHealth?

A systematic review of definitions of eHealth was undertaken by Oh et al (2005). This review found that in the majority of definitions technology was portrayed as a in a

positive light as a way to expand, assist, or enhance human activities, rather than as a substitute for them.

However, Eysenbach provides the following comprehensive definition of the field of eHealth:

> e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology (Eysenbach, 2001).

This definition includes the majority of concepts discussed in the review by Oh et al. (2005) and was the most commonly cited.

According to Ammenwerth et al. (2004, p. 480) eHealth evaluation is:

> "the act of measuring or exploring properties of a health information system (in planning, development, implementation, or operation), the result of which informs a decision to be made concerning that system in a specific context".

Although this definition includes most factors there is the potential for conflict surrounding the lack of generalisability of the results of such evaluations to the wider eHealth community. The next challenge for eHealth is for evaluations to "move beyond testimonials and usage reports, but how much evaluation is enough depends primarily on the user" (Gustafson & Wyatt, 2004, p. 1150). It is essential that the users and their situation is understood and recognised at all stages of the eHealth application lifecycle.

Theoretically the benefits of eHealth appear obvious, however the actual processes of designing, developing, implementing and evaluating systems in healthcare settings has proven to be difficult and uptake has been limited (Ash, Gorman, Seshadri, & Hersh, 2004; Ash, Stavri, & Kuperman, 2003).

Many of the IS implementations within heath have focussed upon administrative and financial systems and less upon the delivery of clinical care (Chaudhury et al., 2006).

> Evaluation of a new system can be seen from differing points of view in the health care system. From an administrator's point of view - whether it works and whether it provides a more efficient service and can contain costs, from the clinicians' point of view - whether it will help to provide a more effective service to patients and from the patient point of whether they will get better care and get better more quickly? (Lindner & Nøhr, 1997)

Thus, it depends upon the perspective that is being used as to whether a summative or formative evaluation is used. For the earlier eHealth systems the use of classical summative evaluation methodologies was the preferred approach to investigating the influence of eHealth systems.

3.4.2 Summative Approaches to Evaluation

Summative evaluations tend to be undertaken at the end of the systems development lifecycle, or at the conclusion of a stage, and are focussed upon looking for the intended benefits (Stoop, Heathfield, de Mul, & Berg, 2004). Many of these have tended to focus on the technological, system performance and economic outcomes

(Heathfield, Pitty, & Hanka, 1998; Lindner & Nøhr, 1997). A few of the most commonly used approaches are briefly discussed below. These approaches tend to be quantitative in nature.

The Theory of Reasoned Action (TRA) (Fishbein & Azjen, 1975) and its revised form, the Theory of Planned Behaviour (TPB) (Ajzen, 1985; Ajzen, 1991) have provided the theoretical foundation for studies into technology adoption and usage. These theories and empirical studies suggest strong links between end-user perceptions and beliefs, attitudinal constructs, behavioural intentions and actual adoption and usage behaviours (Bagozzi, 1981; DeLone, 1988; Igbaria, Zinatelli, Cragg, & Cavaye, 1997; Mathieson, 1991; Mathieson & Keil, 1998; Rose & Straub, 1998; Taylor & Todd, 1995).

More recently research has begun to explore ways of predicting web usage in work environments. Researchers have explored the utility of the technology acceptance model (TAM) (Lederer, Maupin, Sena, & Zhuang, 1998; Lederer, Maupin, Sena, & Zhuang, 2000; van der Heijden, 2003). Research results to date have broadly supported the utility of the TAM. However, all researchers have also identified the need to adapt TAM for web-based environments. These adaptations of TAM have added constructs such as computer self-efficacy (Fenech, 1998) or ease of understanding, ease of finding and information quality (Lederer, Maupin, Sena, & Zhuang, 2000) to predict web acceptance by end-users. Similarly, van der Heijden as yet untested e-TAM model developed to explain web-site revisits has revised TAM by adding the constructs perceived relative usefulness and perceived relative enjoyment (van der Heijden, 2003). This stated it is important to acknowledge that this previous research has been conducted in workplace rather than *non-workplace environments* where use is not mandatory.

Research has highlighted problems with adapting TAM to explore non-workplace usage behaviour within web-portal environments (Steer, Turner, Spencer, & Godfrey, 2001). To enhance the accuracy and usability of TAM for on-going longitudinal studies there will be a requirement to develop a far more complex model that acknowledges many additional variables (Venkatesh & Davis, 2000). For non-workplace environments it is necessary for future research to explore a broader range of motivational and demographic factors to assess their influence on adoption behaviour. More critically, it could be argued that attitudinal models like TAM are simply not suitable as models for examining/predicting user behaviours in web environments (Steer, Turner, Spencer, & Godfrey, 2001).

TAM was derived directly from the generic TRA and has become an important starting point for research aimed at predicting and/or explaining end-user information technology (IT) acceptance and usage behaviour (Davis, 1986, 1989; Davis, Bagozzi, & Warshaw, 1989). The goal of the TAM model is to 'provide an explanation of the determinants of computer acceptance that is general, capable of explaining user behaviour cross a broad range of end-user computing technologies and user populations, while at the same time being both parsimonious and theoretically justified' (Davis, Bagozzi, & Warshaw, 1989: 985).

Since it was first formulated, TAM has been the focus of considerable academic attention (Adams, Nelson, & Todd, 1992; Hartwick & Barki, 1994; Igbaria, Guimaraes, & Davis, 1995; Moore & Benbasat, 1991; Rose & Straub, 1998) and has frequently been revised, adapted and extended, both by its originator (Davis, 1993;

Davis & Venkatesh, 1996; Venkatesh & Davis, 2000) and by others (Chau, 1996; Dishaw & Strong, 1998; Hubona & Geitz, 1997; Szajna, 1996). However, to date there has been little research deploying TAM in the context of non-workplace and non-mandatory IT acceptance behaviour. Regardless of the technical superiority or potential benefits of a particular information system, if it is not used or is under-utilised, the benefits cannot be realised (Chau, 1996). TAM has been used as the theoretical basis for many empirical studies of user technology acceptance and has accumulated ample empirical support (Adams, Nelson, & Todd, 1992; Chau, 1996; Chau & Hu, 2001; Davis, 1989; Davis, Bagozzi, & Warshaw, 1989; Mathieson, 1991; Szajna, 1996; Taylor & Todd, 1995). Despite their limitations TAM and TRA continue to be used in eHealth evaluations (Gallant, Irizarry, & Boone, 2008).

Past research has established the three classic criteria for project success as being on budget, on time and meeting user requirements and specifications. More recent research has demonstrated that other criteria are important and that those above do not account for quality and achieving the project objectives (Brewerton, 1988; Wateridge, 1995). Despite a lack of empirical evidence, project failure has often been attributed to failure to account for behavioural and social factors (Sauer, 1993).

Pinto & Slevin (1987) initially identified factors important in project success and refined them to produce critical success factors which are predictive of successful project management. These were further defined by Pinto and Mantel (1990).

Turner (1993) proposed six criteria for judging project success:

1. the project achieves its purpose
2. it provides satisfactory benefits to the owner
3. it satisfies the needs of the owners, users and stakeholders
4. it meets its pre-stated objectives
5. it is produced to specification, within budget and on time
6. it satisfies the needs of the project team

It is possible for projects to fulfil the majority of these criteria, but fail to meet all criteria. These projects are usually deemed to be successful (Morris & Hough 1987).

Wateridge (1995) considers that Turner's criteria should include "meeting quality constraints". Quality constraints must be determined and agreed upon by all parties prior to the commencement of the project. His research demonstrated a lack of consensus on success criteria. He did however find general agreement that for success, projects must meet user requirements and functionality, on time and in budget. Critically, he found that time and budget continued to be highlighted by project managers at the expense of other criteria. These evaluation methodologies are more frequently used in larger organisational implementations or where budget and time are the major concerns of implementers.

There exists a lack of agreement upon a conceptual definition of user satisfaction and therefore a corresponding lack of agreement on how it should be measured. User satisfaction is often described using terms like "perceived usefulness", "feelings about the system", "system acceptance", and "system friendliness" (Woodroof & Kasper, 1998). Ives et al. (1983, p. 785) define user satisfaction as "the extent to which users believe the information system available to them meets their information

requirements." This definition is limited as it highlights only the user's perceived information requirements and does not include reference to the human computer interaction which research has found to be an important element in satisfaction.

There has been a wide range of research into interface satisfaction (Fisher, 1999; Gould & Lewis, 1985; Gupta, 1994; Johnson, 1992; Shneiderman, 1989; Zmud, Byrd, Sampson Jr, Lenz, & Reardon, 1993) systems success factors (DeLone & McLean, 1992; Deutsch, 1991; Sanders & Garrity, 1998) and user satisfaction (Woodroof & Kasper, 1998). (Ives, Olson, & Baroudi, 1983: 785) define user satisfaction as "the extent to which users believe the information system available to them meets their information requirements." This definition is limited as it highlights only the user's perceived information requirements and does not include reference to the human computer interaction which research has found to be an important element in satisfaction. However, user satisfaction is also a significant factor in evaluation of voluntary usage (Agarwal & Prasad, 1997; Brown, Massey, Montoya-Weiss, & Burkman, 2002; Straub, Limayem, & Karahanna-Evaristo, 1995).

Reflecting the gold standard in medical research, another common method used to evaluate is one that involves or mimics the randomised clinical control trial. These evaluations are similar to comparing the introduction or testing of an information system with the testing of a drug or other discrete intervention. Although, some current eHealth researchers continue to be proponents of this method (Nguyen, Cuenco, Wolpin, Benditt, & Carrieri-Kohlman, 2007) it is argued that it is not possible to obtain an understanding of the full meaning of the outcomes when evaluation is so limited (Kushniruk, 2002; Kushniruk, Borycki, Kuwata, & Ho, 2008; Stoop, Heathfield, de Mul, & Berg, 2004; Stoop & Berg, 2003; Swan, 2007; Urqhart, Currell, & Wainwright, 2000; Wyatt & Spiegelhalter, 1990). So in line with the issues identified above this research acknowledges that randomised controlled trials in isolation cannot address all issues of evaluation and that a range of approaches is desirable as is the use of evaluation methods from other disciplines (Friedman & Wyatt, 2000).

The use of an interpretivist research philosophy in information systems (Klein & Myers, 1999; Myers, 1997; Walsham, 1995a) has been acknowledged as a suitable approach particularly with research studies pertaining to individual behaviours (Bhaskar, 1979; Silverman, 1985).

More recently the focus of eHealth initiatives has been changing so the emphasis is moving from hardware and systems architectures towards more innovative uses of technology. In addition, in parallel with health system changes, eHealth is moving outside the traditional organisational boundaries to include community based implementations. These changes require a revolution in eHealth evaluation criteria and methods (Gustafson & Wyatt, 2004; Jadad & Delamothe, 2003, 2004; Kushniruk & Patel, 2004; Lindner & Nøhr, 1997; Pagliari et al., 2005)

3.4.3 Formative Approaches to Evaluation

Formative evaluations focus on the continuous improvement of the system, with evaluation and review undertaken throughout the development lifecycle (Kushniruk, 2002; Stoop, Heathfield, de Mul, & Berg, 2004).

These formative approaches tend to consist of integrated design methodologies based upon the importance of the input from the different user perspectives. Thus at all stages there is ongoing evaluation and iterative development. Usability is one of the key concepts within these design methodologies. Usability refers to the degree to which the systems are useful, efficient, effective and enjoyable to use (Kushniruk, Borycki, Kuwata, & Ho, 2008)

In healthcare information needs and flows can be difficult to determine precisely (Kushniruk, 2002; Nøhr & Boye, 2008). The environment is very fluid and must remain flexible with shifting goals and priorities dependent upon circumstance (Aarts, Doorewaard, & Berg, 2004; Coiera, 2004).

User-centred design (UCD) methods are becoming increasingly important but during development of many software products continue to have minimal interaction with end-users resulting in poor usability, functionality and resultant low uptake (Waller, Franklin, Pagliari, & Greene, 2006). Within UCD methods such as human computer interaction (HCI) and participatory design (PD) are examples of constant evaluative development methodologies.

HCI designers do not strictly follow a sequential process. In contrast problem definition and design are treated as co-dependent processes that are refined over time. This means that a stage can be revisited at any point, ensuring that feedback from users, resulting from evaluation processes, can be incorporated into the final product (Waller, Franklin, Pagliari, & Greene, 2006). Within HCI, usability testing and simulation has been successfully employed in the identification and prevention of technology induced errors (Borycki & Kushniruk, 2005; Kushiniruk, Triola, Stein, Borycki, & Kannry, 2004; Kushniruk, Triola, Borycki, Stein, & Kannry, 2005).

To ensure the most accurate task information, greater user input into design and provide a greater ownership of the product participatory design recognises the benefits of including users as equal members of the design team (Shneiderman, 1998). Within PD users are involved at all levels through the use of exploratory, experience-driven activities (Preece, Rogers, & Sharp, 2002)

There is a vast array of methods employed within HCI and PD. Think aloud protocol analysis is one observational technique becoming more popular within usability testing. In this method the user speaks their thoughts as they are performing routine tasks using information systems. Think aloud is often used in usability laboratory research with the interactions captured on video recordings and matched through the analysis process. This method often rapidly identifies problems which can then be rectified in consultation with the user (Price, 2008).

Simulation provides a partial solution to the problem of evaluating effectiveness of ICTs whilst preserving patient safety and privacy. In many healthcare organisations it is preferable to use large scale simulation laboratories to for learning centres including the integration of health information systems into clinical practice environments (Sanderson, 2007)

Video observation can be undertaken in conjunction with think aloud protocols or simulations or in isolation. Video observation can be carried out where and when the task being examined is occurring. This method can be very cost effective and does not require a full simulation laboratory (Kushniruk, Borycki, Kuwata, & Ho, 2008; Nøhr & Botin, 2007; Nøhr & Boye, 2008).

3.4.4 The Problem with Patients

Approaches to eHealth are becoming more patient-centred. However, frequently these approaches are info-centric and prioritise the informational effect, that of providing the patient with more information. This assumes that axiomatically through the provision of additional information patients are gaining better care and it ignores the psychosocial, attitudinal and contextual factors that are key to good healthcare.

With the move towards more patient-centric eHealth and the increasing introduction of eHealth applications into people's homes there is a need to recognise the multiple complexities involved in evaluating these systems. There is no single clear evaluation method to be adopted in this environment.

Any evaluation needs to be consistent with UCD methodologies to ensure ongoing iterative development to meet the end users' requirements. The users within a patient-centred eHealth system can have wide ranging variability in terms of competencies, aims, adoption, use and access. This research is situated in the difficult area of exploring the influence of an online ICT tool (online patient diary) on participant's experiences within a clinical controlled trial where participants have limited or no experience as technology users.

3.5 Health Outcome Evaluation

Health evaluation has its foundations is a number of backgrounds and disciplines but principally medical research, epidemiology, statistics and more recently social science methods and theory (Øvretveit, 1998). Until recently it has not been greatly influenced by general evaluation theories from programme or educational evaluation and the dominant perspectives remain experimental and economic. From this it is easy to understand why the focus of health outcome evaluation is based around the same perspectives.

Health outcomes research is defined as:

> the measurement of the value of a particular course of therapy. Health outcomes research is based on the principle that every clinical intervention produces a change in the health status of a patient and that change can be measured (CancerWEB Project, 1998).

The emphasis upon the measurement of outcome has become more widespread over the past decades. The tools derived for this purpose are usually referred to as health 'outcome measures' (Duckworth, 1999). A health outcome measure is a measure of change in health, at a defined point in time, as a result of one or more healthcare processes. The selection, use, interpretation and evaluation of outcome measures resulted in considerable debate and controversy within the health literature (Horner & Larmer, 2006). Outcomes research relies on instruments to measure the results of particular healthcare interventions upon the experiences of people involved. Through linking the care people get to the outcomes they experience, outcomes research has become the core component for the development of improved monitoring and quality of care.

Aligned to the rise in the emphasis upon outcome measurement has been the trend towards evidence-based medicine (EBM). EBM promotes the improvement of patient care through the use of up to date high quality, research evidence to make healthcare decisions. Generally this involves a hierarchy of evidence, which places randomised

controlled trials (RCTs) and other population level research above other research (Bluhm, 2005). This hierarchy has cause significant concern in many quarters due to the reduced emphasis upon individuals and the primacy of population level evidence. Through this method clinical guidelines are developed and practice can be standardised throughout the healthcare sector. Many professional organisations use the evidence available from RCTs and systematic reviews to develop clinical practice guidelines as a service to their members. These guidelines are not mandatory but once available there can be significant pressure upon individual practitioners to adhere to them, particularly for medico-legal reasons (Timmermans, 2005).

One of the core components of EBM, and the most popular method of evaluating health outcomes from interventions is the RCT. Using RCTs assessment of the impact of an intervention are clinically centred or objective. They tend to concentrate on a few measurable outcomes but ignore the patient experience and unexpected effects that cannot be measured easily. Furthermore with extended RCTs it is difficult to isolate a single intervention so that outside factors do not effect the stability of the intervention (Øvretveit, 1998).

There are many claims that the RCTs are the gold standard in healthcare evaluation. This is the result of the dominance of the scientific research paradigm within which healthcare exists (Holmes, Murray, Perron, & Rail, 2006). RCTs merely reflect good experimental design, although there are many potential shortcomings in the design and implementation of RCTs (Grossman & Mackenzie, 2005).

The primacy of the RCT has begun to attract some attention (Smith & Pell, 2003). For example he evaluation of alternative medicine therapies, or non-mainstream interventions, highlights problems with the EBM hierarchy of evidence. Within these areas it is frequently not possible to undertake RCTs to gain the highest level of evidence (Borgerson, 2005).

Of particular concern is the potential for outcome bias within RCTs, dependent upon funding source. Ridker and Torres (2006) reported upon surveys of RCTs published over the decade 1990-2000. The differences in reported outcomes reflected that RCTs funded by not-for-profit organisations were less likely to report positive outcomes than those funded by for-profit organisations. These results raise questions around the validity of trial design and ethics. However, most importantly they raise concerns regarding the quality of the evidence being used to treat the most vulnerable in our communities, the sick.

Therefore there is a requirement for some scepticism when dealing with EBM. This scepticism is evident in the general population when they are confused by the often conflicting evidence presented to them regarding recommended health behaviours. Thus there is a need to ensure some balance within health outcome evaluations and it is also important to continue to provide for individualised care within the population based models (Kassirer, 1998).

It is critical that health outcome evaluation based upon RCTs use valid and relevant measures. For a measure to be valid the instruments need to be understood by all those using them, not only by those evaluating them (Shumway, Chouljian, & Rozewicz, 2003). There is a wide range of standardised outcome measures and thus it is very difficult, but important, for those required to develop, complete, and interpret outcome measurements to share a common understanding of the questions and responses for each instrument (Shumway, Chouljian, & Rozewicz, 2003).

The range of individual measures used to evaluate health outcomes for the clinical controlled trial in which this research thesis is located were discussed in section 2.5. However, it is evident from the discussion above that although health outcome measurement is available there remains a requirement for deeper understanding of interventions at an individual or sub-population level. This understanding cannot be gained through current health outcome measures.

3.6 Reflections

This chapter has provided a review of selected literature across a range of domains that are relevant to this research. It has introduced a number of current issues which are impacting upon the healthcare sector both in Australia and internationally.

It has provided a basis for the reader to understand the core concepts and practices that underpin the practice of chronic disease self-management and introduced a number of different CDSM programmes.

The issue of meaningfully evaluating both eHealth and health outcomes has been presented. Through this literature the problems of combining all three of these domains have become evident.

This research is located at the intersection of the three domains of chronic disease self-management, eHealth evaluation and health outcome evaluation. It aims to investigate the influence of an online patient diary on the health outcomes and experiences of people with COPD participating in a mentored self-management clinical controlled trial.

Chapter 4 provides a detailed explanation of the methodology used within this research to address the primary research questions identified in section 1.3.2.

Chapter 4 Methodology

> Spectacles magnify one set of factors rather than another and thus not only lead analysts to produce different explanations of problems that appear, in their summary questions to be the same, but also influence the character of the analyst's puzzle, the evidence he assumes to be relevant, concepts he uses in examining that evidence, and what he takes to be an explanation.....different conceptual lenses lead analysts to different judgements about what is relevant and important (Allison, 1971, p. 251).

4.1 Introduction

This chapter provides the details of the research methodology used in the conduct of this research. The chapter addresses the philosophical stance adopted, the research strategy and procedures employed, the data analysis techniques applied and outlines the approach to the interpretation and discussion of the research.

- Section 4.2 addresses the philosophical position adopted. Due to the exploratory nature of this research a subjective ontology utilising an interpretative epistemology was utilised as the most appropriate research philosophy.
- Section 4.3 discusses the three phase research strategy employed in the study. Phase 1 uses descriptive statistics to describe the overall project participants and explore differences between the different groups. Phase 2 involved conducting and analysing 36 semi-structured interviews in relation to the experiences of 12 individual participants. The interviews were conducted with the selected participants, their primary mentors and the research assistant – these interviewees formed the care triad. Analysis was undertaken using within case and cross-case analysis. Phase 3 developed 12 individual case studies combining the data from Phases 1 and 2 to provide a rich insight into the individuals' experiences within the clinical controlled trial.
- Section 4.4 addresses the specific research procedures employed in each phase.
- Section 4.5 describes the techniques used to collect the data. Data were gathered from a number of sources including quarterly surveys conducted through the cases' participation on the Pathways Home for Respiratory Illness Project and semi-structured interviews with the care triad.
- Section 4.6 describes the application of data analysis techniques used to analyse the statistical and interview data. It details the coding processes employed within the analysis of the triad interviews and the development and analysis of the individual case studies.
- Section 4.7 outlines the approach taken to interpretation and discussion of the research.
- Section 4.8 concludes the chapter with a summary reflection on the research methodology.

4.2 Research Philosophy

This thesis investigates the influence of an online patient diary on the health outcomes and experiences of people with chronic obstructive pulmonary disease (COPD) participating in a mentored self-management clinical controlled trial. The research is undertaken within the boundaries of a clinical controlled trial with its own aims and objectives (as described in 2.4).

At a practical level, there remains limited knowledge on how patients experience CDSM interventions and what factors frame and/or constrain their involvement and ability to derive benefit. There is also a need for more sophisticated approaches to understand and evaluate the influence of ICTs on patients engaged in CDSM interventions. Approaches that can meaningfully explore the gap between assessments of ICT benefit for a cohort of patients versus those for an individual patient.

As a result the research philosophy was to look at cohort and individual patients using both quantitative and qualitative data within a exploratory epistemology and ontology.

Before commencing any research a researcher must assess their fundamental philosophy about the nature of reality, knowledge and human behaviour. These philosophies influence the choices of method appropriate for research (Doolin, 1996; Guba & Lincoln, 1994). A subjective ontology utilising an interpretative epistemology was embraced as the most appropriate for the exploratory nature of this research. Exploratory research is useful to "become familiar with the basic facts, setting, and concerns" (Neuman, 2000:22).

There is a general tendency among researchers to view epistemology and method as being inseparable (Howe, 1988, 1992). However, the social sciences employ a greater pragmatism in their research and are advocating the separation of method from epistemology (Bryman, 1984; Onwuegbuzie & Leech, 2005a, 2005b). These researchers conclude that differences in paradigm or epistemology do not prevent qualitative researchers from employing techniques generally associated with quantitative research or vice versa. This movement encourages the use of a wider range of data collection techniques whilst still enabling the researcher to operate within the appropriate ontology and epistemology.

Given that this research seeks to investigate the influence of an online patient diary on the health outcomes and experiences of people with COPD, it is important to focus on the attitudes, insights and experiences of those individuals involved. Therefore it is most appropriate to conduct the research within a subjective interpretive paradigm whilst not limiting the data collection methods or analysis techniques.

Olson (1995) argues that the distinction between qualitative and quantitative data is purely a distinction of data types and does not predict how these data should be treated. The research philosophy is of more importance in determining how data is analysed than the data type per se. In this research the numeric data collected within the controlled trial will be used, alongside the field data, as it presents the results of the RCT and can be used to further contextualise the experiences these people have had with technology and self-efficacy and self-management development. It is important to incorporate and build upon the RCT data to extend the evaluation past the cohort analysis level to investigate the experiences of the individual.

4.2.1 The Ontology

Ontology is the study or theory of existence and refers to the perceived nature of the world around us. Ontology addresses the issues of whether the empirical world is considered to be independent of humans, objective, or having existence through the action of humans and recreating it, subjective (Burrell & Morgan, 1985; Orlikowski & Baroudi, 1991). In essence, "the issue of ontology lies prior to and governs subsequent epistemological and methodological assumptions". (Chua, 1986: 604).

A subjective ontological view is best described as one, which emphasises the subjective behaviour or reasoning which determines how people construct their own reality within the constraints of society's agency (Orlikowski & Baroudi, 1991). This view implies that the researcher assumes that the social world is produced and reinforced by humans through their action and interactions.

In order to gain a rich insight into the patient-centred eHealth domain, a research philosophy using a subjective ontological approach is considered most fitting. Given the nature of the research questions proposed in this study it is appropriate to employ an interpretative epistemology to engage with the participants, their mentors and the research assistant to gain a deep insight into the influence of an online patient diary on the health outcomes and experiences of people with COPD.

Hence the research seeks to enhance the individual case studies with contextual information about the use of technology and the subjective experience of the patients with regard to their own self-management or with regard to COPD per se. Thus the use of statistical survey data within a subjective ontology will contribute to contextualising the individuals' experience of this technology into their lives, in regard to the impact on self-management, and so adding richness to the overall case study data.

To do this it is necessary to adopt a research philosophy that treats numeric data and non-numeric data in a similar way as a means of providing an insight into the subjective experience of the individual patients and the opportunity to explore aspects of these experiences between cases. Hence the most appropriate research ontology for this research is a subjective one.

4.2.2 The Epistemology

This study is of an exploratory nature and it is the intent of the researcher to examine the rich contextual data as much as possible without forming any preconceived ideas. It is inappropriate to strive for objectivity and testability at the expense of forgoing the chance to highlight the context and conditions in which the study is conducted. However, as the research is being carried out within the bounds of a wider controlled trial, which employs quantitative multi-method research techniques, the access to and potential impact of the positivistic epistemological stance of some of the associated researchers must be acknowledged.

The term epistemology refers to beliefs and assumptions about the way in which knowledge is constructed and acquired (Cavaye 1996; Neuman 1997). These beliefs relate to how one might begin to understand the world and communicate this knowledge to others (Burrell and Morgan 1979). Humans acquire knowledge through tradition, agreement, belief and experience. The way in which this knowledge is

produced differs. Much of our knowledge comes from others and the fact that they agree that this knowledge is real leads us to accept it (Babbie 1998).

An interpretative research approach is considered the most appropriate means to identify and analyse the role and impact of an IT solution, the online patient diary, developed to support the chronically ill in developing self-management skills and self-efficacy. The interpretivist approach is based on an ontology in which reality is subjective, a social product constructed and interpreted by humans as social actors according to their beliefs and value systems (Darke *et al*, 1998).

Interpretivism seeks relevance in the research (Keen 1991) by explicitly including investigation of the context of the phenomenon under study. The interpretive research philosophy is commonly adopted in IS research as the most appropriate research approach to understand the context surrounding interactions within the environment under investigation (Doolin 1996).

The nature of interpretative research is such that the researcher does not enter a social setting with a priori constructs, but allows constructs to emerge whilst the researcher is in the field learning about and trying to understand the phenomenon. In using an interpretivist epistemology it is possible to "understand phenomena through accessing the meanings that participants assign to them" (Orlikowski & Baroudi, 1991:5).

Utilising an interpretative approach enables the researcher to gain a deep understanding of the phenomenon under study while acknowledging the associated subjectivity. In contrast employing a positivist approach uses statistical or experimental controls to minimise experimental bias and assure objectivity but in order to achieve this goal the contextual aspects of the data are removed to produce generalisable and reproducible results (Kaplan and Duchon, 1988).

Similarly the experiences of participants who do not take up the opportunity to use the available ICTs can provide much insight into the techno-centric or info-centric methods by which ICTs are traditionally measured. Thus although it is possible to measure the number and frequency of transactions upon a system the actual experience of the user or non-user can only be truly captured through utilising an open-ended, qualitative, subjective, interpretivist research approach.

The research philosophy adopted is one which enables the researcher to consider the subjective experience of individual patient yet at the same time capture and treat numeric data. The resulting research philosophy is one which embraces openness, with a subjective ontological position and an interpretivist epistemology.

4.3 Research Strategy

This section will address the research strategies used to conduct this study. The process of data collection was undertaken in two stages. Due to the fact that this research was being undertaken within the context of a wider clinical controlled trial it was determined that examination of the quantitative data collected on the whole trial cohort would be useful in informing the subgroup selection and determining its representativeness. It was also important in addressing the first research question and its associated research objectives. The collection and use of these data are discussed in sections 2.5, 4.5 and 4.6.

The use of these secondary data from the trial was to establish the relationship between the use of the online patient diary and the trial outcome measures at cohort and sub-group levels and to answer the first research question. Due to membership of the project team the researcher was involved in the processes of data management, retrieval and cleansing of these data, both for this research and the trial as a whole.

The primary data collection utilises multiple case studies based on an interpretivist approach. As this research is of an exploratory nature a multiple case research strategy is deemed appropriate in order to gain an in-depth understanding of the context or phenomenon (Cavaye, 1989). It is considered that case study research is highly suited to studying phenomena that have no well defined a priori constructs and relationships. The information gathered from the multiple case studies will be explored through interpretation of the data using qualitative research methods.

To enhance the primary data collection method the results of the data collected at quarterly intervals within the clinical controlled trial will also be examined. These data provide a longitudinal picture of changes in both the clinical scores and the self-reported quality of life indicators of participants involved in the research and so add a further dimension to the current study.

The research strategy and methods employed to collect this information relies upon the use of:

- Descriptive statistics generated from the broader controlled trial but treated within the research philosophy above; that is as contextualising data for the subsequent in depth case studies; and
- Multiple case studies of individual participants' experiences in the process of developing self-management skills, through the available interventions.

A discussion of the use of descriptive statistics and multiple case studies for inductive theory building is presented in the next section.

4.3.1 Descriptive Statistics

Descriptive statistics provide simple summaries about the sample and the measures and are used to describe the basic features of the data in a study. Descriptive statistics are typically distinguished from inferential statistics in that descriptive statistics are used simply to describe what the data shows. In contrast, inferential statistics are used when trying to reach conclusions that extend beyond the immediate data alone and to infer findings to more general conditions (Rowntree, 1981).

Descriptive statistics can be used to present population descriptions as a means of summarising the vast amounts of data collected to a more manageable form (Haslam & McGarty, 2003). Within this research descriptive statistics are used to describe the clinical and health outcomes at various cohort or subgroup levels. They are used in Phase 1 to explain the impact of the intervention in clinical and health outcome terms and so address the first research question. The descriptive statistics are subsequently used to enhance the descriptions and understandings within the individual case studies developed in Phase 3 and addressing the second research objective of the second research question.

4.3.2 A Case Study Approach

The examination and understanding of the context in which information systems can be used to support those with chronic conditions to self-manage their condition is particularly important when the research is of an exploratory nature. This is indicative of areas where there is little understanding of how and why processes or phenomena occur, or where the experience of individuals and the context of actions are critical (Benbasat, Goldstein, & Mead, 1987; Darke, Shanks, & Broadbent, 1998). The theory surrounding the impact and use of eHealth tools by people suffering chronic conditions is not well developed, as the phenomenon is dynamic and not yet mature or settled.

In Information Systems research the application of a case study research strategy is considered a plausible and accepted research strategy (Lee, 1989) particularly where research and theory has been formulated at an early stage with little theoretical base (Galliers, 1992; Galliers & Land, 1997).

Case study research may involve a positivistic (Benbasat, Goldstein, & Mead, 1987; Lee, 1989; Yin, 1989) or interpretative epistemology either employing quantitative, qualitative or a combination of the two research methods. Although past IS researchers have used case study research in a positivistic manner there has been a notable increase in an interpretivist use of case study research (Walsham, 1995b).

Interpretative case studies have been widely used in the social sciences (Silverman, 1998), and are gaining wider acceptance in the Information Systems discipline. Although Yin (1984) supported the use of case research from a positivist perspective, his belief that case studies can be best used to explore "how" and "why" questions supports an interpretivist approach to using case study strategy (Walsham, 1995b).

The case study approach has the capacity to bring four dimensions to interpretivist research (Urquhart, 1999). It has the ability to:

- produce rich insights from the data;
- draw specific implications;
- develop concepts within the data; and
- provide a base to generate theory.

Specifically, through the ability to produce rich insights from the data the use of a case study approach provides a coherent strategy to explore the influence of an online patient diary on the health outcomes and experiences of people with COPD within a mentored self-management programme. The study incorporates the use of multiple case studies and descriptive statistics to improve the rigour and validity of the data analysis.

4.3.3 Multiple Case Study Approach

The use of multiple case studies as opposed to a single case study provides the researcher with an opportunity to observe the research phenomenon in a variety of different settings. The multiple case study approach allows analysis from and the cross comparison of multiple sources (Darke, Shanks, & Broadbent, 1998). There are no specific guidelines determining an appropriate number of cases to use, however it is beneficial to utilise multiple cases in this research as the use of ICTs in supporting

self-management is an emerging research area. Eisenhardt (1989) suggest the number of required case studies depends on how much new information is likely to be gained by the addition of extra cases to the research.

As this research investigates the influence of an online patient diary on the health outcomes and experiences of people with COPD it is important to incorporate a number of cases that can provide evidence of a wide range of experiences. Thus, this study utilises twelve individual cases studies.

The advantages of case study research strategies include the ability to study a phenomenon in a natural context, and to study a large number of issues and different aspects related to the phenomena. Multiple case studies provide an avenue to develop and refine concepts for further study and enable researchers to compare concepts in different contexts (Cavaye, 1996). A further strength of using multiple case studies is that it may provide literal replication Yin (1994) and opportunities for natural generalisation. The analysis of multiple cases may increase theoretical replication where results are similar and other cases can be selected to produce contrasting results for predictable reasons (Darke, Shanks, & Broadbent, 1998).

This research develops case studies around each of the individual participants. These cases provide a multi-perspective view upon the experiences in the trial for each of the individual participants but also enable the development of comparisons across the cases (see Chapters 6 and 7).

4.4 Research Procedures/Techniques/Design

This interpretive study investigates the influence of an online patient diary on the health outcomes and experiences of people with COPD within a mentored self-management programme. The research strategy and methods employed to collect this information relies upon the use of:

- Controlled trial statistics; and
- Multiple case studies.

The research is conducted using a three phase approach. Phase 1 involves the controlled trial statistics. These data were collected quarterly as part of the Pathways Home Project controlled trial and included demographic, clinical and self-reported survey data. These data are examined at three levels:

1. Control versus Intervention level;
2. All IT users versus All Non-IT users; and
3. IT group versus Non-IT group.

The demographic data are also examined at the level of Intervention group versus Research subgroup. This was for the purposes of establishing the representativeness of the research subgroup.

Phase 2 involves exploring the semi-structured interview data across the IT and non-IT groups to compare the two groups for similarities and differences in regards to experiences. Thirty six interviews were undertaken, forming 12 individual case studies. Within each case three interviews were conducted; one with the participant, one with their primary mentor, and one with the research assistant. These three

interviews formed the case triad and were used to inform the research from multiple perspectives.

Phase 3 involves combining data from phases one and two for each of the twelve cases to explore in detail the inter-relationships amongst factors (including the online patient diary) influencing patient's health outcomes and experiences over the duration of the trial. Phase 3 provides a rich and highly detailed picture of the individual participant's health outcomes and experiences to allow the researcher to investigate the influence of the online patient diary. Each phase is represented in figure 4.1.

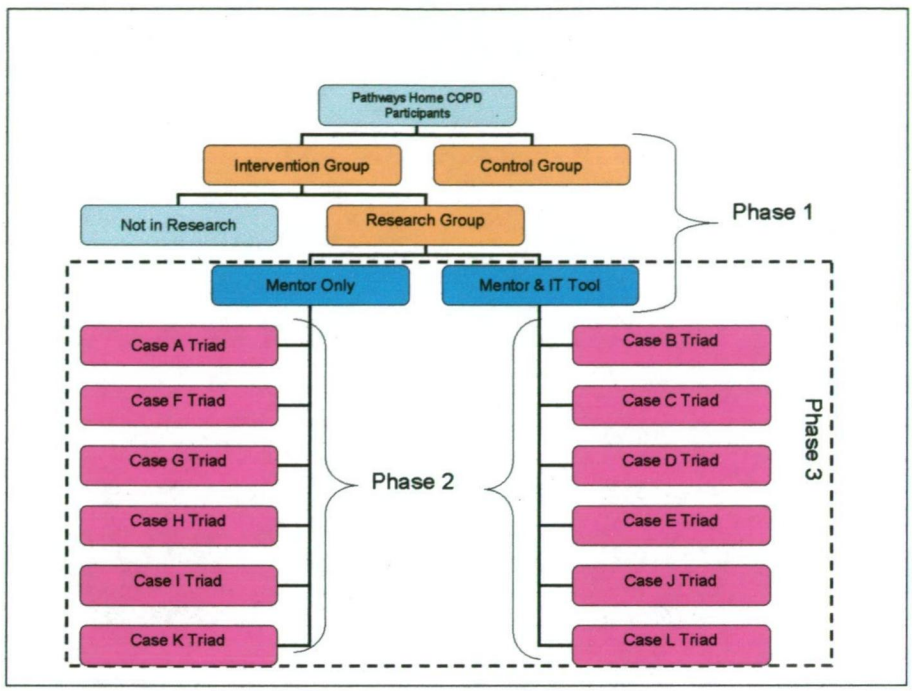

Figure 4.1 Research Methodology Phases

A discussion of the data collection methods and techniques in relation to each phase is presented in the next sections.

4.5 Data Collection Techniques

This section describes the data collection techniques involved in each phase of the research. The data analysis processes will be described in section 4.6.

4.5.1 Phase 1 - Controlled Trial Data

This section presents an overview of the data collection methods for the controlled trial statistics. All data were collected at five quarterly intervals while participants were actively engaged in the trial. The initial data was collected in hospital by the recruitment officer. All subsequent data was collected in the participant's home by the research assistant.

The controlled trial data is divided into three types of data, demographic data, clinical indicator scores and self-reported survey data (see Section 2.5.2). The demographic data was collected once at enrolment, the other data types were collected at five distinct points over the duration of each person's participation in the Pathways Home

for Respiratory Illness Project. The data were all collected over the period June 2005 to November 2007. It was stored within a secure de-identified database. Collection, storage and use of the data were consistent with the ethical constraints for human research in Australia and controlled and reported under the medical ethics approval Ref No: H0008370.

4.5.2 Phase 2 – Triad Interviews

In previous research triad interviews have been employed with each member of the triad present at the same interview (Aeffect Inc, 2001; Clendon, 2006-7; Davidson, Obonsawin, Seils, & Patience, 2003; Duff, Johnston, Moore, & Goren, 2007). These interviews typically involve children or adolescents and are undertaken as group interviews to encourage open discussion. Other researchers have used the concept of dyad interviews where conversations between the healthcare practitioner and the patient are recorded and these form the basis of the interview transcript (Zoffmann, 2004; Zoffmann & Kirkevold, 2005).

In this research the triad interviews were undertaken as individual interviews, each relating to an individual participant. There were a number of reasons for this method being employed. Firstly it was deemed important that each interviewee was given an opportunity to express their own opinions without feeling under pressure. Secondly the controlled trial methodology required that the intervention be delivered with minimal face-to-face contact, thus the mentors and participants could not be interviewed together. Finally due to their illness and decreased mobility the participants were interviewed in their homes.

Within the context of the research it is important to explore the differing perspectives regarding what people say they do, what they think they do and what they actually do (Nøhr & Botin, 2007). To do this we use the triad as each interview offers a different perspective on the participant's experiences and so gives the opportunity to provide the additional aspect of what other people, the mentors and research assistant, observe in the participant's behaviour. These differing views do not negate each other, nor is additional weighting attributed to any particular interviewee. They are used to provide a broader frame for exploring the participant's experiences. However, during the interview analysis the triad interviews were considered as providing three different perspectives of the same experience and so analysed as a single instance.

Individual semi-structured interviews were conducted with the selected research subgroup of project participants (see section 4.5.2.1 for selection process), their primary mentors and the research assistant who visited participants in their homes – this formed the care triad.

4.5.2.1 Case Selection

Individuals involved in this research were all participants in the intervention group of the Pathways Home for Respiratory Illness Project. Recruitment of participants into the project was discussed in section 2.5.3. As a result of their inclusion in the project participants shared a number of characteristics but are also quite diverse. Those included in this research were from amongst the early recruits into the project. This was to ensure they had completed a minimum of nine months within the project prior to being interviewed. This period of time was identified as many participants

withdrew from the trial prior to the nine month period and also this gave the participants and mentors a long period of exposure to all the trial processes.

As recruitment into the project was initially slow and due to the introduction of additional researchers to the team, the available population was limited to the initial twenty recruits to prevent contamination or over exposure of participants. Within this initial population the number of available participants was further reduced due to individuals withdrawing from the project. A pool of 16 participants who met these criteria were identified and approached to be engaged in this research.

Initial contact with those eligible for participation was through their mentors. This provided them with the opportunity to refuse to participate in a non-threatening environment as the mentor was a familiar person with whom they had developed a rapport. Three people decided they did not want to participate.

Once they had consented the researcher contacted them directly by telephone to discuss the purpose of the research, confirm their willingness to participate and to organise a time for the interview to be conducted. One participant withdrew consent at this stage.

Once the participants had confirmed their availability the appropriate mentors were approached for consent for interviews. They universally agreed to this. Finally the research assistant was approached. This recruitment process resulted in 12 individual cases being selected. These participants were equally divided between the two groups of IT cases [N=6] and non-IT cases [N=6]. The individual cases are demographically described in Table 4.1.

For the purposes of this thesis the participants have been identified using pseudonyms. This was undertaken to make the process of reading and the differentiation of the cases easier. The mentors are referred to as participant pseudonym's mentor (e.g. Albert's mentor) and the research assistant similarly (e.g. Albert's RA). When discussing/comparing the case as a whole or all cases in a specific group the cases are referred to as case A, B, C etcetera, with the first letter of the case referring to the first letter of the participant's pseudonym (e.g. Case A refers to Albert).

Table 4.1: Interview Participant Demographics

	Date of Birth	Age when Enrolled	Sex	Marital Status	Suburb	Postcode	Education Level	Carer	Mentor ID	Online Patient Diary
Albert	14/02/1929	76	Male	Married	Huonville	7109	Year 7-10	Wife	2001	No
Beryl	11/06/1946	59	Female	Married	Warrane	7018	Year 7-10	For Husband	2009	Yes
Constance	17/11/1942	62	Female	Widowed	Bridgewater	7030	Year 7-10	None	2012	Yes
Doreen	24/07/1944	61	Female	Widowed	Mornington	7018	Undergrad Degree	Grand-daughter	2009	Yes
Edward	22/05/1939	66	Male	Married	New Town	7008	Year 7-10	None	2014	Yes
Francine	31/03/1933	72	Female	Widowed	West Hobart	7000	Year 7-10	None	2016	No
Gaye	6/12/1929	76	Female	Widowed	Gagebrook	7030	Year 7-10	Neighbour	2013	No
Harold	10/08/1934	71	Male	Single	Battery Point	7004	Primary	None	2015	No
Ivan	10/10/1934	71	Male	Widowed	Rokeby	7019	Year 7-10	None	2007	No
Janice	3/02/1942	64	Female	Divorced	Kingston	7050	Advanced Diploma	Professional carer daily	2018	Yes
Kerry	3/05/1947	59	Female	Married	Rokeby	7019	Year 7-10	For Husband	2009	No
Lola	11/11/1947	58	Female	Divorced	Geilston Bay	7015	Year 7-10	Home Help	2012	Yes

4.5.2.2 The Interview Process

The interview process started with the researcher providing information about the research aims and objectives. Participants in each interview were asked if the researcher could record the conversation on a tape recorder. In all cases permission was granted. A total of thirty-six interviews were conducted, three for each case study. The duration of each interview was approximately an hour for the participants and mentors, but significantly less time for the research assistant.

All interviews were face-to-face with the participant in a location convenient to the interviewees. All those suffering from chronic conditions were interviewed in their homes. The mentors and the research assistant were interviewed in their workplace. In all instances case notes were taken during the interview process and at the conclusion of each interview the researcher reflected on the conversation and retained personal comments and thoughts about the meeting along with the interview transcript interview notes. These were later collated and re-organised into a format ready for data analysis. At the completion of the interview the tapes were transcribed in preparation for data analysis.

Three separate semi-structured interview question formats were developed, one for each interview group. The questions are provided in Appendix 9 and the rationale for the questions is discussed below.

4.5.2.3 The Participant Question Format

A semi-structured question format was used to gather information about the participant experiences during the period of involvement with the research. The questions were formulated to encourage participants to discuss issues relating to the study without imposing limitations or constraints on how the questions may be answered (Doolin, 1996). The questions were arranged into four broad sections.

- Section 1: Engagement with the project

The aim of the first section of questions was to collect background information about the participant's engagement with the project. Questions were framed to explore the participant's understanding about the aims of the project and their reasons for participating.

- Section 2: Self-management and self-efficacy

The questions in the second section focused specifically on the participant's experiences of their COPD and how this may have altered as a result of participating in the project. For example, before the trial if you felt a bit of a change in your condition what did you do? Has this action changed now? What do you do now? Further questions were also asked about the use of the paper-based diaries for symptom monitoring and the interactions with the mentors.

- Section 3: IT and its role

Section three questions were asked to explain the impact of the introduction of computers on the participant's development of self-management skills and self-efficacy. Questions were posed to elicit an understanding of the reasons why participants adopted computers and their experiences using the computer.

- Section 4: Suggestions for change

Section four questions were aimed at identifying any further information that the participants may consider important that was not covered previously.

4.5.2.4 The Mentor Question Format

The mentor questions were formulated to gain information about the mentor's experiences with the project and to expand upon and confirm the participant interviews. The mentor questions were divided into three sections.

- Section 1: About you and the program

Section one questions were asked to gain an insight into the mentor's understanding of the project and their reasons behind participating in the project.

- Section 2: Computer experiences

Section two questions were asked to explore the mentor's experiences and attitudes towards computers prior to involvement in the project and also during the project.

- Section 3: Individual Participant

Section three questions were specific to the individual participant. These questions were formulated to explore the mentor's perceptions of how the participant changed over the period of the project and their attitude to computers in relation to the project. There were two mentors who were involved in more than one interview. All questions were asked during each interview to ensure that any changes that had occurred in the intervening period were detected.

4.5.2.5 The Research Assistant Question Format

The research assistant questions were formulated to gain information about the research assistant's understanding of the project and to expand upon and confirm the participant interviews. The research assistant questions were divided into two sections. As there was only one research assistant for these participants the questions in section 1 were only asked once.

- Section 1: General one off questions

Section one questions were to explore the research assistant's understanding of the project and gain some background about their duties in relation to the project.

- Section 2: For each individual participant

Section two questions were formulated to gain additional information about the individual participants from the research assistant's perspective.

4.5.3 Phase 3 - Individual Case Studies

The individual case studies were developed through the process of combining the data from phases one and two of the methodology. Although the triad interviews formed the central data collection, the individual case studies were developed through synthesising multiple data sources. These included:

- The triad interviews;
- Case specific baseline demographic, clinical and survey data collected as part of the clinical controlled trial;

- Records of participants' diaries and diary entry data; and
- Field notes and observations collected during direct interactions with the participants, their families, their mentors and the research assistant.

Through combining all these data a rich and deep understanding of each individual participant's experiences within the trial was developed. The merit of using multiple in depth case studies is discussed in section 4.3.3. Other researchers have previously identified the use of them to provide rich descriptions of emergent research areas (Benbasat, Goldstein, & Mead, 1987; Yin, 1989).

4.6 Data Analysis

This section describes the various approaches employed to analyse the data. It is divided into three sections, each reflecting one of the phases of the methodology.

Data analysis is the breaking down of data to reveal its characteristic structure and elements (Dey, 1993). Analysis is directed towards answering the major research question. However, new research questions may become evident during analysis. With qualitative research the analysis begins with the formulation of a research design. There are many possible data collection techniques available to the qualitative researcher. The act of selecting the most appropriate techniques can be viewed as the start of the analysis, and is essential to the analysis (Huberman & Miles, 1994).

Description is the basis for analysis but through analysis a different view of the data can be gained. So analysis is an iterative process, with each iteration offering a new perspective upon the data (Dey, 1993).

4.6.1 Phase 1 – Controlled Trial Data Analysis

Phase 1 analysis involved the use of descriptive statistics to provide a high level analysis of the effect of the trial on a number of clinical and other outcome measures at 3 levels: intervention [N=55] versus control group [N=51]; intervention group (ICT adopters [N=20] versus ICT non-adopters [N=35]); and, amongst participants selected for interview (ICT adopters [N=6] and ICT non-adopters [N=6]). Additionally demographic data is analysed in a manner to provide evidence regarding the representativeness of the participant groups selected for examination in the ICT adopters and ICT non-adopters groups, or case groups.

The Phase 1 analysis (see Chapter 5) utilises descriptive statistical methods to provide a brief exploration of the clinical controlled trial data in direct relation to the first research question and its related research objectives[2].

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

RQ1: RO1 To describe the impact of the overall intervention on health outcomes; and

RQ1:RO2 To explore the impact of the online patient diary on health outcomes within the intervention.

[2] A comprehensive inferential statistical analysis of the trial is currently being undertaken by the Pathways Home for Respiratory Illness Project research team.

From a statistical perspective there are a number of ways in which these data could be presented and analysed. In this thesis for ordinal data, such as marital status and educational level, participant numbers for each grouping at enrolment and completion are used. For all other data types mean is used for the measure of central tendency and standard deviation as the measure of variance. These measures are appropriate as the research seeks only to observe current frequency data on the cohort or groups in terms rather trying to predict for wider populations (Haslam & McGarty, 2003).

Effect size is a mathematically derived standard measure enabling comparison of the magnitude of the difference between the means of two groups (Kazis, Anderson, & Meenan, 1989). Effect size for the change in outcomes over time is calculated by dividing the difference between the mean change for the relevant group's outcomes at enrolment and completion by the standard deviation at enrolment.

4.6.2 Phase 2 – Triad Interview Analysis

Phase 2 qualitative analysis involved coding of all thirty six interview transcripts and drawing on the principles of grounded theory generated a series of core categories identifying concepts and themes across the twelve cases including those relating to patients: understanding of the trial; impact of their social environment; the severity of their disease; and, the impact of a computer and online patient diary.

As this section of the study focuses on the analysis and interpretation of the interview transcript, a recursive process of analysis and interpretation and analysis reinterpretation of the text is employed. The task of the researcher is to reveal insight and meaning within the text. This requires the researcher to read "between the lines" and extract the underlying meaning of the text as opposed to what is found on the surface. The process of examining the text also adds an element of subjectivity (the influence of the researchers own viewpoint) during the analysis stage.

The role of the researcher in this study is one of an outsider-observer. The researcher is considered external to the care triad; as a consequence the process of collecting and interpreting the data by the researcher is a subjective one. The advantage of being an observer external to the triad is that information can be divulged in an open, frank and confidential manner provided a level of trust is established.

In phase 2 a cross group analysis of the triad interviews was undertaken to look at similarities and differences between the two case groups. In undertaking this cross group analysis the semantic relationships both within and between the IT and non-IT groups are explored. The goal of cross-case analysis is to link empirical findings across cases (van der Blonk, 2003). Cross-case analysis provided a framework in which an interpretation could be developed which reflected both the individual cases as well as all the cases.

The groups are of interest both for their uniqueness and their commonalities, in a similar manner to the individual cases (Ayres, Kavanaugh, & Knafl, 2003; Stake, 1995). Comparing the groups enabled the commonalities to be explored and reflected on, in particular their significance. The commonalities increase the explanatory power of the core categories that emerged during the coding process. The following section describes the approach undertaken to analyse each individual interview transcript.

Primarily, Phase 2 addresses the first research objective of the second research question:

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO1 To qualitatively explore the impact of the online patient diary.

Additionally, the analysis undertaken in Phase 2 provides the basis for the development of the in-depth case studies within Phase 3 (see section 4.6.3 and Chapter 7).

4.6.2.1 Interview Analysis

This section describes the approach taken to the analysis of the interview transcript data. Drawing on the principles of grounded theory and domain analysis this analysis combines two qualitative data analysis techniques. These methods utilise an inductive approach to theory generation whereby theories, concepts and models are derived directly from the data or grounded in the data. The inductive theory building process relies on an iterative cycle of reading and re-reading the qualitative data to detect emergent themes and constructs embedded or grounded in the data (Neuman, 2000).

Initially open, axial and selective coding of each individual interview was undertaken. The first level of data analysis draws upon the principles of the grounded theory coding practices initially developed by Glaser and Strauss (1967). Central to their methodology are three stages of coding, open coding, axial coding and selective coding. Their approach involved transforming the data to extract the underlying relationships and themes, not those that are merely apparent on the surface. Strauss (1987) proposed that the coding criteria aimed to look beyond the codes, which condense and categorise the data but also look for links with other phenomena and dimensions. Typically the process of axial coding aims to search for and recognise these possible associations and other dimensions relating to other phenomena (Coffey & Atkinson, 1996).

A code is an abbreviation or symbol applied to a segment of words or phrases in order to classify the words. Codes are categories. They usually derive from research questions, hypotheses, key concepts and important themes. They are retrieval and organising devices that allow the researcher to spot quickly, pull out, then cluster all the segments relating to particular questions, hypotheses, concepts or themes (Miles & Huberman, 1994: 56).

Coding is a means of identifying and grouping data, both verbal and non-verbal. In this research coding was used to analyse all the interview transcripts. A top-down method of analysis was used. This involved first open coding the interviews, then axial coding the open codes. From there selective coding was undertaken. The selective codes were then examined in relation to the critical success factors from the literature. This process is described in detail below.

Open coding

Open coding is the first pass through the data. The data is read and the meaning absorbed. Themes are identified and codes assigned to these themes. These themes may come from the research question, concepts in literature, terms used by participants, or new thoughts which arise from the data (Strauss, 1987).

The process of open coding involved immersion in the interviews, this was undertaken through listening to the audio recording of each interview whilst open coding the transcriptions. The field notes recorded at the time of interview were also reviewed during this process. This technique enabled the researcher to reflect upon the person and the interactions that occurred outside the recorded interview as well as what was recorded. Through this method the process of open coding was undertaken with the interviewee and circumstance in mind in an attempt to limit the possibility of misinterpretation.

Open coding of each of the interviews was undertaken. The level of analysis required to generate codes can vary from by phrase, line, sentence or paragraph or by a holistic analysis of an entire document (Creswell & Plano Clark, 2007; Sarkar, Lau, & Sahay, 2001). The unit of analysis was at phrase level. This allowed the interviews to be summarised according to the main code of the phrase. At this stage every phrase was open coded.

During open coding it is important to assign meaning to the sentence, not just summarise what is said. Figure 4.1 is an excerpt from the interview transcript from Janice. It demonstrates the initial codes assigned to the various aspects of the research transcript. At this stage, the initial open codes tended to be more descriptive than inferential. At this stage the codes were unfocused and 'open'. By coding in every way possible, it allowed for multiple directions of the phenomena to be examined before becoming selective.

Therefore in the initial stages of open coding, there may be several different codes assigned to the same phenomenon, however, this was addressed in subsequent passes of the data. It is important to maintain a list of codes that explains what the codes mean. This is essential for maintaining consistency throughout research.

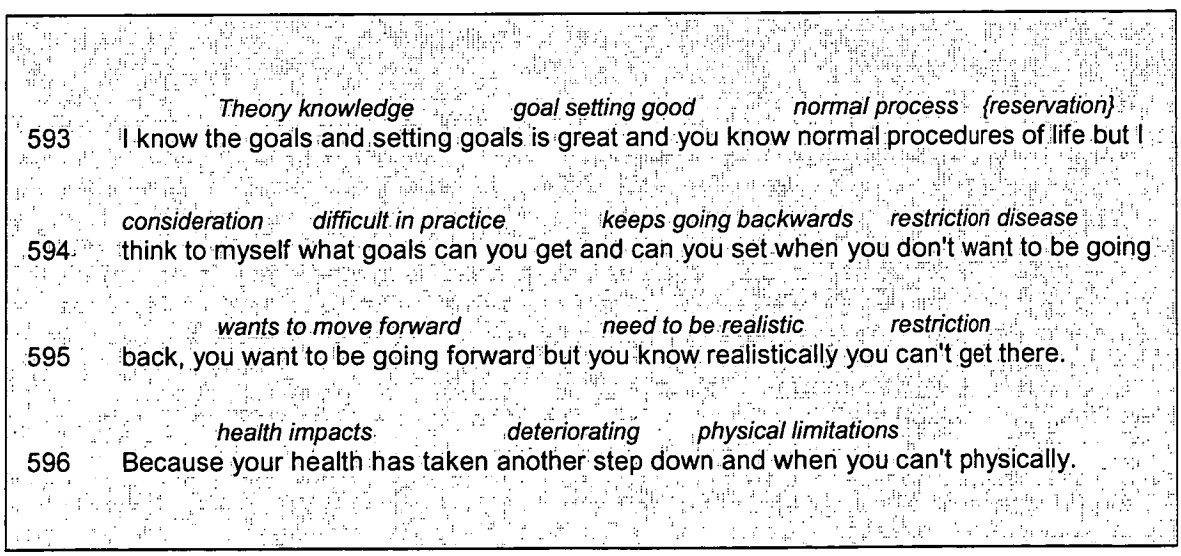

Figure 4.2: Examples of the Initial Open Codes Janice Interview

Once the transcript had been coded, a spreadsheet was compiled with all the initial open codes. The initial codes were entered into the spreadsheet in one column and the corresponding line number for each code was incorporated into the spreadsheet beside each code. The line numbers allowed the researcher to easily refer to the exact spot in the data at a later date.

At this stage, there were over 5,000 codes. There were several codes which were repeated a number of times throughout the transcript. Therefore, the first stage of organising and reducing the number of initial open codes involved identifying multiple occurrences of the same code within the transcript. By sorting the spreadsheet alphabetically, multiple occurrences of the same code were readily identified. Having one code represented by multiple line number references further condensed the number of codes.

The second strategy adopted by the researcher for condensing the open codes involved collating similar open codes together. During the initial open coding phase the researcher was less concerned about consistency of terminology but more concerned with letting the code flow openly. However, the researcher was aware that the same phenomenon may have been coded differently. The more transcripts the researcher coded, the more consistent the codes assigned became. Once the open codes had been identified for each interview the axial coding was undertaken.

Axial Coding

Axial coding is the second pass through the data. It looks at the open codes rather than at the data. Additional codes may appear and it can aid the identification of key concepts. Axial coding examines factors such as cause, consequences, conditions, interactions, strategies and processes (Strauss, 1987). The initial set of issues is reorganised according to common themes. This results in an increased depth of examination of the themes and reinforces the connection between the data and the concepts (Neuman, 2000).

At the axial coding stage the open codes were sorted into common groups. This was initially undertaken with each individual interview. The axial codes for the individual interviews were then grouped into the individual case triads. Each triad consists of the project participant, their primary mentor and the research assistant who visited the participant quarterly in their homes and assisted with the quality of life surveys.

The codes relating to each of the triad interviews were then examined for areas of similarity and difference. These areas of similarity or difference may indicate different priorities of the members of the triad in relation to the trial and the interview questions. No judgement or prioritisation of one perspective over another was involved in this analysis, although positive or negative stances surrounding the same codes were recorded. At this stage duplicate or similar codes within each triad were identified. This enabled the number of axial codes to be refined by grouping similar codes together under a single name. Through this process within case analysis was undertaken initially at an axial code level.

Within-case analysis offers a method for exploring the contextual factors at a case level. Scheepers and Scheepers (2003) suggest that during within-case analysis, the importance of context is re-emphasised. The dilemma of multiple case study research in general is that the researcher must develop an interpretation of the data that reflects the individual case's experience as well as applying across all the accounts that constitute the data set (Ayres, Kavanaugh, & Knafl, 2003). This was dealt with through the within case analysis and through the development of the holistic case studies in Phase 3 (Chapter 7).

Once each triad had been analysed they were grouped according to whether the participant had chosen to adopt the online patient diary or not. Through this grouping

process it became evident that there were close similarities in the axial codes. Through a further refinement those codes of similar meaning were renamed to produce a set of axial codes that were common across all triads. The final stage of the coding process involved examining the selective codes and the data in relation to the literature.

The grounded theory techniques applied selectively to assist with data analysis provided a mechanism for systematically organising the data. It did not provide a comparison across cases. Therefore, to provide a broad framework with which to compare cases, the axial codes and categories which emerged from within-case analysis phase and the semantic relationships that existed between the axial codes were compared and contrasted with all other cases. Therefore not only were individual cases compared with other cases within their group but also with all the cases outside the group. This was to ascertain whether any cases 'leaked' from one group into another on the basis of this more detailed level of analysis. Comparing and contrasting the cases at the axial code level rather than at a higher level of aggregation such as the selective code level was employed as a strategy by the researcher to minimise the potential for the aggregated findings to become irrelevant to all cases.

Selective Coding

Table 4.2 demonstrates the axial codes and related selective codes (core categories).

Table 4.2: Core Categories

Axial Code	Core Categories
health behaviour health general health impact health system support mechanisms health understanding	personal experience
diary outcome health knowledge project impact self-management behaviour self-management knowledge	outcome
diary feedback diary use goal setting mentoring process project impression project knowledge project reason symptom monitoring	project experience
computer attitude computer experience computer impact computer initiation computer issue computer rejection computer use	technology experience

The process of selective coding not only seeks to identify core categories, it also seeks to identify whether any linkages exist between the core categories. The core category is "the central phenomenon around which all the other categories are related" (Strauss and Corbin, 1990: 116). Through an iterative process and through revisiting the open codes, potential relationships between the axial codes were identified. These relationships were used to classify the codes into core categories (see section 6.2.2).

Once the core categories were identified each was explored in detail looking at the relationships between the underlying axial codes within the categories. Additionally, relationships between the core categories emerged and through this process a conceptual model was created (see Figure 6.5).

4.6.3 Phase 3 Analysis – Case Study Examples

The final phase of the analysis, contained in Chapter 7, drew up all the available data for each case. In this phase in-depth case studies of the twelve individual participants were constructed from the quantitative and qualitative data collected in the previous phases. These case studies provided a means for exploring the relationships between individual differences and experiences within the trial and specifically addressed the final research objective:

RQ2: RO2 To explore the wider influence of the online patient diary on individual patients' experiences through an holistic examination of factors and their interactions revealed by both the clinical trial and qualitative data

Additional individual data relating to the cases was available and used at this level. These data included the actual participant daily symptom monitoring diary data and field notes and observations recorded during the ICT training process. At the individual case level it was also possible to examine the frequency of participant/mentor interactions which could not be meaningfully used in the first phase.

Through combining at individual level it was possible to construct a view over time of the participant's experiences, from a number of perspectives, and to understand the variations that occurred within the quantitative data in context.

These comprehensive case studies were developed for each of the cases. However, within the context of this thesis it is not possible to present them all. Therefore, to illustrate the data analysis procedures employed in the final phase of this study three representative case examples from the twelve cases are used. These examples reflect the very different experiences of participants who used the online patient diary and those who did not. The analysis of the three case examples, a non-IT user with no benefit from the trial, an IT rejecter with benefit and an IT user with benefit, is presented in detail to illustrate to the reader the comprehensive data analysis processes used with each of the twelve cases involved in this research.

- Albert is a gentleman who completed a symptom monitoring diary daily but chose not to use the online patient diary. In addition no member of the care triad could identify any benefit he gained from his participation in the trial.
- Beryl is a lady who chose to use the online patient diary but then rejected it. She continued to complete her paper diary daily and used the diary to become

more familiar with her symptoms. She achieved improvements in her ability to self-manage her condition.

- Lola is a lady who chose to use the online patient diary. She completed a diary daily for the duration of the trial. She achieved improvements in her ability to self-manage her condition.

4.7 Interpretation and Discussion

This section outlines the approach in Chapter 8 taken to interpret and discuss the data analysed using the methods discussed above. The interpretation occurred in relation to each of the four research objectives. Thus the quantitative data was used to interpret the first research question and its related research objectives. Through this process it was possible to provide answers to this research question and identify potential issues with these interpretations.

Next the second research question was addressed using the triad interview data analysis as its basis. This interpretation initially identified the outcomes of the online patient diary. To understand the impact of the online patient diary it was essential to understand the experiences and outcomes of the participants who did not use the online patient diary as well as those who did.

However, significant categories which arose from the qualitative analysis were related to the participant's experiences of the trial but outside the online patient diary. These findings were interpreted separately in order to address the final research objective. Within this interpretation it was essential to draw upon some data analysis from cases other than those specifically presented in Chapter 7.

Finally a discussion of the interactions of various areas identified within the interpretation is presented. This discussion revisits not only the research questions and how the methodology and interpretation has revealed deep insights, but also relates some of these insights back to the higher level paradigmatic questions raised in Chapter 1.

4.8 Reflections

This chapter outlines the philosophical position adopted by the research. A subjective ontology utilising an interpretative epistemology was deemed the most appropriate for the exploratory nature of the research.

The application of a qualitative multiple case study strategy using twelve unique cases was employed to acquire a rich data source from a range of participants involved in the Pathways Home for Respiratory Illness Project. The use of multiple case studies enabled a rich insight into the participant's experiences, views and meanings associated to the role and impact of ICTs on self-management and self-efficacy for self-management in COPD sufferers.

This chapter has discussed the research design and methods used to collect the data from multiple cases. A series of interviews were conducted with participants involved in the Pathways Home for Respiratory Illness Project, their mentors and the research assistant using semi-structured interview frames. The question frameworks were designed to gather opinions, experiences and meanings about the participant's

involvement in the project and their use of ICTs in relation to monitoring their health and development of self-management skills.

Importantly this chapter has described the method by which the triad interview data was analysed to provide both within case and across group analysis in relation to both the axial codes and core categories.

The final section of this chapter discusses the process used to interpret and discuss the research. The interpretation of the research and the study's findings is found in Chapter 8. The next chapter presents the analysis of the clinical controlled trial data at the four levels of:

4. Control versus Intervention level
5. All IT users versus All Non-IT users
6. Intervention versus Research subgroup (demographic data only)
7. IT group versus Non-IT group

The data analysis of the twelve cases using a high-level grounded theory approach and the coding procedure associated with this analysis is presented in Chapter 6.

Chapter 5 Phase 1 Analysis

Where is the life we have lost in living?

Where is the wisdom we have lost in knowledge?

Where is the knowledge we have lost in information? (Eliot, 1934)

5.1 Introduction

This chapter will examine the Pathways Home for Respiratory Illness Project data using descriptive statistics. The analysis is conducted in relation to the following groupings:

- Control [N=51] and Intervention [N=55];
- All IT Users [N=20] and Non-IT Users [N=35]; and
- IT Cases [N=6] and Non-IT Cases [N=6].

Each of these groups is important as they allow the research to answer the first research question and its research objectives:

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

RQ1: RO1 To describe the impact of the overall intervention on health outcomes; and

RQ1: RO2 To explore the impact of the online patient diary on health outcomes within the intervention.

In addition to the groupings described above the demographic data is analysed in terms of the following Intervention [N=55] and Case Groups [N=12]. This is to determine the similarities and differences between the whole intervention group and the selected case subgroup used for the in-depth analysis and so explore the representativeness of the case group.

The analysis contained within this chapter is important in that it provides information as to the quantitative effects of the overall trial intervention in relation to the outcome measures. It is also important for the purpose of validating data on the participants selected for qualitative follow-up. This analysis provides the first stage for exploring the intervention outcomes in relation to the online patient diary.

- Section 5.2 describes the analysis techniques employed in this chapter.
- Section 5.3 describes the demographic data relating to the four groups.
- Section 5.4 provides an analysis of selected clinical indicators in relation to the three groups.
- Section 5.5 provides an analysis of the self-reported survey data relating to self-efficacy for self-management and quality of life measures across the three groups.
- Section 5.6 provides a summary of the symptom monitoring diary usage data.
- Section 5.7 provides a reflection upon the analysis.

5.2 Statistical Analysis Techniques

This section provides details of the statistical analysis techniques employed throughout this chapter.

5.2.1 Descriptive Statistics

Descriptive statistics provide simple summaries about the sample and the measures and are used to describe the basic features of the data in a study. Descriptive statistics are typically distinguished from inferential statistics in that descriptive statistics are used simply to describe what the data shows.

Central tendency is the middle value or typical value of the data, and is measured using the mean, median, or mode. The measure of central tendency used within this analysis is the mean. The mean is a most commonly used measure of central tendency and is the sum of the values divided by the total number of items in the set. Measures of central tendency are not appropriate for some of the data such as marital status and educational level (Haslam & McGarty, 2003). These ordinal data are presented

Standard deviation is the average amount by which the scores differ from the mean, it considers all scores (Rowntree, 1981). It is the measure of variance used within this chapter. In addition the range is presented for some measures.

5.2.2 Effect Size

Effect size is a mathematically derived standard measure enabling comparison of change between or within groups (Kazis, Anderson, & Meenan, 1989). Effect size for the change in outcomes is calculated by dividing the difference between the mean change for the relevant group's outcomes at enrolment and completion by the standard deviation at enrolment, see formula below.

$$\frac{\overline{X_2} - \overline{X_1}}{SD_1} = \text{Effect Size}$$

Cohen (1988) determines that a value of 0.20 to 0.40 is considered to be small, 0.50 to 0.70 is moderate and 0.80 or greater indicates a large size effect.

Within this analysis effect size is used to describe changes over time in relation to the various study sample groups[3]. A measure of effect size is used to establish any change in the self-reported quality of life survey data gathered over the period of the project.

5.3 Demographics

The first stage of the analysis explores the demographic data collected on all participants within the Pathways Home for Respiratory Illness project and examines it in terms of the following relevant groups:

[3] Further statistical analysis is being undertaken by the Pathways Home for Respiratory Illness Project team and will be reported in detail in forthcoming papers.

- Control and Intervention to determine overall project similarities and differences;
- IT Users and Non-IT Users to look at the characteristics of those within the intervention who did or did not use the online patient diary;
- Intervention and Case Groups to determine the similarities and differences between the whole intervention group and the selected case subgroup used for the in-depth analysis; and
- IT and Non-IT Cases to determine the similarities and differences in these groups.

5.3.1 Sex and Age

This section examines the sex and ages of participants in each of the groups. It commences by providing some information about an additional group, those who chose not to participate in the trial.

During the recruitment process 60 people who were eligible to participate were approached but they declined to participate. These are described in Table 5.1.

Table 5.1: Refusals by Sex and Age.

	Control Group			Intervention Group		
	Male	Female	All	Male	Female	All
Number	11	12	**23**	20	17	**37**
Mean Age	71.18	71.83	**71.52**	73.20	72.00	**72.65**

The ages of the refusals were higher for all categories which may indicate that the older members of the COPD population did not wish to participate[4].

Control and Intervention Groups

In the control group 48.15% of males did not complete whereas 25% of females did not complete. In the intervention group 44.44% males and 29.73% of females did not complete.

In both groups the average age of the males was higher that that of the females with the females in the intervention group being the youngest group see Table 5.2.

Table 5.2: Control and Intervention Groups by Sex and Age.

		Control Group			Intervention Group		
		Male	Female	All	Male	Female	All
Enrolment	Number	27	24	**51**	18	37	**55**
	Mean Age	70.81	68.38	**69.67**	71.11	64.41	**66.60**
Completion	Number	14	18	**32**	10	26	**36**
	Mean Age	70.21	67.50	**68.69**	71.80	64.54	**66.56**

COPD is thought to be more prevalent among men than women, a finding usually attributed to higher smoking rates and more frequent occupational

[4] The reasons for refusal were also collected and will be analysed by the Pathways Home for Respiratory Illness research team

> exposures of significance for men. However, smoking prevalence has increased among women and there is evidence that women may be more susceptible to the adverse pulmonary function effects of smoking than men (Chapman, Tashkin, & Pye, 2001, p. 1691).

With increasing smoking rates and earlier uptake amongst women this may be a reason for more women being diagnosed with COPD and at a younger age (Chapman, Tashkin, & Pye, 2001; Mannino, 2002; Petty, 2000; Tzanakis, Anagnostopoulou, Filaditaki, Christaki, & Siafakas, 2004).

IT users and non-IT users

A much larger proportion of those choosing to use online patient diary were female (80%). The mean age of those choosing to use in both the male and female groups was lower than those choosing not to use the online patient diary.

Table 5.3: IT Users and non-IT Users by Sex and Age

		IT Group			Non-IT Group		
		Male	Female	All	Male	Female	All
Enrolment	Number	4	16	20	14	21	35
	Mean Age	67.75	61.44	62.7	72.07	66.67	68.83
Completion	Number	2	14	16	8	12	20
	Mean Age	68.00	63.14	63.75	72.75	66.17	68.80

All those of the IT group who did not complete the 12 months participation died prior to completion whereas only 26.67% of the Non-IT group died, the remainder withdrew prior to completion.

Intervention and Case Groups

The mean ages of the males and females of both the intervention and case groups are similar. The ratio between the participant numbers between each group was approximately 5:1 (Table 5.4).

Table 5.4: Intervention and Case Groups by Sex and Age

	Intervention Group			Case Group		
	Male	Female	All	Male	Female	All
Number	18	37	**55**	4	8	**12**
Mean Age	71.11	64.41	**66.60**	71.00	63.75	**66.17**

Thus in terms of sex and age the case group is representative of the total intervention group.

IT and Non-IT Cases

The IT cases are younger than the non-IT cases this is relevant to both the males and females. There is only one male and five females in the IT cases with equal numbers of each sex in the non-IT cases (Table 5.5).

Table 5.5: IT and Non-IT Cases by Sex and Age

	IT Cases			Non-IT Cases		
	Male	Female	All	Male	Female	All
Number	1	5	6	3	3	6
Mean Age	66.00	60.80	61.67	72.67	68.67	70.67

From the project data it appears that for the participants within the project the older age group, and particularly older males, are less likely to use the online patient diary. Those more likely to use the online patient diary are younger females.

5.3.2 Marital Status

In the context of the intervention it is important to consider factors such as whether participants live alone and their marital status. These variables may provide the basis for unexpected findings. These data are described below in terms of the research groups.

Control and Intervention Groups

At enrolment 45.10% of participants in the control group and 47.27% of the intervention group were married. At enrolment 27.45% of the participants in the control group and 27.27% of the intervention group were widowed. However, 39.13% of the married participants in the control group and 42.31% of the married participants in the intervention group did not complete the twelve month participation period.

55.56% of divorced control did not complete and 57.14% of the divorced intervention did not complete.

Table 5.6: Control and Intervention by Marital Status

	Enrolment		Completion	
	Control	Intervention	Control	Intervention
Single	2	2	2	1
Married	23	26	14	15
De facto	1	2		1
Widow	14	15	10	13
Divorced	9	7	4	3
Separated	2	2	2	2
N/R		1		1
Total	51	55	32	36

IT users and non-IT users

At enrolment 40.00% of the IT users were married and 35.00% were widowed. At enrolment 51.43% of the non-IT users were married and 42.86% were widowed. At completion 31.25% of the IT users were married and 43.75% were widowed.

37.50% of married IT users did not complete with 44.44% of married non-IT users not completing the full twelve months. All divorced in non-IT did not complete as opposed to 25% of the divorced in the IT group. However, it must be noted that the IT users who did not complete all died and did not withdraw from the project, only 4 or 21.05% of the non-IT users died, the remaining 78.95% withdrew prior to completion.

Table 5.7: Marital Status by IT and Non-IT Users

	Enrolment			Completion		
	IT	Non-IT	All	IT	Non-IT	All
Single		2	2		1	1
Married	8	18	26	5	10	15
De facto		2	2		1	1
Widow	7	8	15	7	6	13
Divorced	4	3	7	3		3
Separated	1	1	2	1	1	2
N/R		1	1		1	1
Total	20	35	55	16	20	36

Intervention and Case Groups

There were a greater proportion of widowed people in the case group (41.67%) than in the intervention group (27.27%). However, there were a greater proportion of married people in the intervention group (47.27%) than in the case group (33.33%). These differences are not unexpected due to the availability sampling of the case group.

Table 5.8: Marital Status by Intervention and Case Group

	Intervention	Case Group
Single	2	1
Married	26	4
De facto	2	
Widow	15	5
Divorced	7	2
Separated	2	
N/R	1	
Total	55	12

IT and Non-IT Cases

There were no single people in the IT cases and no divorced people in the non-IT cases, there were no people in de facto relationships or separated in either of these groups (Table 5.9). These may relate to the small numbers in each group and the overall low numbers of single, divorced, de facto and separated people in the intervention group and reflect upon both the characteristics of those who consent to participate in medical research and the COPD population as a whole.

Table 5.9: Marital Status by IT and Non-IT Cases

	IT Cases		Non-IT Cases	
	Male	Female	Male	Female
Single			1	
Married	1	1	1	1
Widow		2	1	2
Divorced		2		

Marital status appears to have an effect upon completion of the project participation there was a low completion rate associated with divorcees, although for some this was due to death rather than withdrawal. However, being divorced may have an impact upon completion, with all non-IT divorcees withdrawing prior to completion. This

appears to be offset by the IT use where no divorced IT users withdrew. IT users are more likely to live alone and complete their full period of participation.

5.3.3 Education Level

The highest education level of all participants was collected at enrolment. The purpose of collecting these data was to identify any similarities or trends in education levels between the groupings.

Control and Intervention Groups

At enrolment 90.02% of the control group and 89.09% of the intervention group had an education level of year 12 or below. Of those completing the full twelve month intervention 93.75% of the control group and 86.11% of the intervention group had a highest education level of year 12 (Table 5.10). These high levels of people with lower education levels may be due to characteristics of people with COPD in Tasmania or may be due to the characteristics of people choosing to participate in medical research in Tasmania.

Of the participants who failed to complete the 12 months participation 73.68% of the control group and 89.47% of the intervention group had an education level of year 12 or below..

Additionally 74.51% of the control group and 78.18% of the intervention group had an education level of year 10 or below. Of those completing the full twelve month intervention 84.38% of the control group and 75.00% of the intervention group had a highest education level of year 10. Of the participants who failed to complete the 12 months participation 57.89% of the control group and 84.21% of the intervention group had an education level of year 10 or below.

Table 5.10: Education Level by Control and Intervention Groups

	Enrolment		Completion	
	Control	Intervention	Control	Intervention
Year 6 or below	10	10	6	5
Year 7-10	28	33	21	22
Year 11	2	1		
Year 12	6	5	3	4
Certificate	4	3	1	2
Diploma		1		1
Bachelor degree	1	1	1	1
N/R		1		1
Total	51	55	32	36

IT users and non-IT users

All but two of the IT users had a highest education level of year 12 or below, with 88.89% being year 10 or below. Similar results are reflected in the non-IT group, with 88.57% having a highest education level of year 12 or below. At completion all of the IT group who did not complete and all but one of the non-IT group had a highest education level of year 12 or below (Table 5.11).

Table 5.11: Educational Level by IT and Non-IT Users

	Enrolment			Completion		
	IT	Non-IT	All	IT	Non-IT	All
Year 6 or below		10	10		5	5
Year 7-10	16	17	33	13	10	22
Year 11	1		1			
Year 12	1	4	5	1	3	4
Certificate		3	3		2	2
Diploma	1		1	1		1
Bachelor degree	1		1	1		1
N/R		1	1		1	1
Total	20	35	55	15	21	36

Intervention and Case Groups

89.09% of the intervention group and 83.33% of the case group had a highest education level of year 12 or below, with 78.18% of the intervention group and 83.33% of the case group having a highest education level of year 10 or below (Table 5.12). This demonstrates that in terms of the education level the Case Group was quite representative of the total intervention group.

Table 5.12: Education Level by Intervention and Case Group

	Intervention	Case Group
Year 6 or below	10	1
Year 7-10	33	9
Year 11	1	
Year 12	5	
Certificate	3	
Diploma	1	1
Bachelor degree	1	1
N/R	1	
Total	55	12

IT and Non-IT Cases

All of the non-IT cases and 66.67% of the IT cases had a highest education level of year 10 or below (Table 5.13).

Table 5.13: Education Level by IT and Non-IT Cases

	IT Cases		Non-IT Cases	
	Male	Female	Male	Female
Year 6 or below			1	
Year 7-10	1	3	2	3
Diploma		1		
Bachelor degree		1		
Total	1	5	3	3

High percentages of the participants had education levels of year 12 or below. However, education level appears to have had little impact upon the decision to use the online patient diary.

5.4 Clinical Indicators

The clinical indicators reported here were collected as part of the Pathways Home for Respiratory Illness project. A full analysis of the clinical data is being undertaken by the clinical members of the project team and will be reported in other publications. The analysis and reporting of these data here is primarily as an indication of the results gained through the project and is presented in relation to the following relevant groups:

- Control and Intervention to determine overall project similarities and differences;
- IT Users and Non-IT Users to look at the characteristics of those within the intervention who did or did not use the online patient diary; and
- IT Cases and Non-IT Cases to determine the similarities and differences in these groups.

5.4.1 Mini Mental State Examination

The Mini Mental State Examination (MMSE) is a measure of cognitive functioning and is explained in greater detail in section 2.5.1.1. However, briefly scores of 27 and above are considered normal, scores of between 23 and 26 indicate a borderline condition and scores of 22 and below are abnormal. People with scores greater than 21 were eligible for inclusion in the project; once enrolled a decrease in MMSE score alone did not result in exclusion. Mean MMSE scores for each grouping at each time period are reported here with the standard deviations of these scores.

Control and Intervention Groups

At enrolment both the control and intervention groups had similar mean MMSE scores of 27.31 and 27.09 respectively. Over the course of the project participation period each of these groups increases their mean MMSE by approximately one point (Table 5.14). These changes may be due to the initial low scores recorded by some participants at recruitment due to a residual hypoxia from their acute exacerbation. However, the higher mean completion MMSE may also be due to the attrition of those with lower scores due to their inability to comprehend the complex processes within the project. Similar trends are evident across all the different groupings (Tables 5.14-5.16).

Table 5.14: MMSE by Control and Intervention Group

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Control	27.31	± 2.14	27.04	± 2.90	27.03	± 3.09	27.66	± 2.85	28.42	± 2.05
Intervention	27.09	± 2.17	27.53	± 2.22	27.14	± 2.04	28.18	± 1.60	28.17	± 1.68

Table 5.15: MMSE by all IT Users and all Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All IT Users	27.60	± 1.82	27.42	± 2.57	27.60	± 1.99	28.22	± 1.77	28.38	± 1.67
All Non-IT Users	26.80	± 2.32	27.63	± 1.95	26.82	± 2.06	28.14	± 1.49	28.00	± 1.72

Table 5.16: MMSE by IT Cases and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
IT Cases	27.50	± 1.05	27.50	± 1.05	27.17	± 1.17	27.50	± 2.07	28.00	± 1.90
Non-IT Cases	26.50	± 1.88	27.33	± 2.34	25.67	± 1.86	27.50	± 1.38	27.83	± 1.47

There was little fluctuation in mean MMSE scores and generally these scores were within the normal ranges with an occasional dip to the top end of the borderline category. Minor increases in MMSE scores from enrolment to completion may be due to the initial adverse effect of their exacerbation and hospitalisation.

5.4.2 Spirometry

Spirometry is a measure of timed expired and inspired volumes, and from these it is possible to calculate how effectively and how quickly the lungs can be emptied and filled. Spirometry readings are influenced by the age, sex, height, weight and ethnic origins of the participant. At the time of undertaking spirometry a predicted value for each measure is also calculated based upon the participant's age, sex, height, weight and ethnic origins. A further calculated measure of the percent of predicted results for each measure is provided.

5.4.2.1 Percent Predicted FEV1

The FEV1 is a measure of the forced expiratory volume at 1 second. This measure indicates the degree of large airways disease of a participant. A FEV1 of 60%–80% predicted signifies mild COPD, 40%–59% predicted signifies moderate COPD and an FEV1 <40% predicted signifies severe COPD (McKenzie, Frith, Burdon, & Town, 2003) The percent predicted FEV1 is used in this instance to provide an indication of the level of respiratory function within each group.

The mean percent predicted FEV1 for both the control and intervention groups at enrolment placed the participants in the severe category. There was however, a large range of entries as indicated by the large standard deviation. The completion percent predicted FEV1 measures for each group was higher than at enrolment and for the control group this indicated that the mean was just within the moderate range (Table 5.18). Given that it is rare for people with COPD to improve their respiratory function this change is probably attributable to the more severe cases not continuing their participation through to 12 months. A similar representation occurs for the other groups (Tables 5.17-5.19).

Table 5.17: Percent Predicted FEV1 by Control and Intervention Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Control	36.08	± 13.62	40.68	± 18.61	36.34	± 16.55	40.12	± 18.6	40.75	± 16.46
Intervention	34.87	± 14.21	38.95	± 16.27	39.78	± 14.99	37.91	± 18.09	37.68	± 14.04

Table 5.18: Percent Predicted FEV1 by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All IT Users	32.25	± 15.78	36.79	± 17.71	36.79	± 17.71	38.53	± 22.42	42.38	± 16.07
All Non-IT Users	36.41	± 13.20	40.74	± 15.13	38.77	± 12.19	37.45	± 14.66	34.28	± 11.68

Table 5.19: Percent Predicted FEV1 by IT and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
IT Cases	32.83	± 9.54	43.00	± 22.32	41.00	± 18.67	37.60	± 22.41	46.80	± 19.94
Non-IT Cases	34.33	± 12.75	42.17	± 17.69	44.83	± 11.39	35.50	± 14.95	36.33	± 14.69

In the IT cases the increased mean percent predicted FEV1 is due to the fact that one participant, with severe COPD, was unable to complete the spirometry test. This group also demonstrates higher standard deviations in all measures except the enrolment measure.

Essentially these results indicate that the participants in the project had moderate to severe large airways disease and that their condition was worse at enrolment due to the fact that they were enrolled at the end of an acute exacerbation. The recovery time from an acute exacerbation varies but it has been determined to be a prolonged process, frequently without complete return to pre-exacerbation lung function (Seemungal, Donaldson, Bhowmik, Jeffries, & Wedzicha, 2000; Spencer & Jones, 2003).

5.4.2.2 Percent Predicted FEF 25-75

The forced expiratory flow 25-75 (FEF 25-75) is the average flow of air from the lung during the middle portion of the expiration. Typically low FEF 25-75 indicates respiratory conditions affecting the small airways. As with the FEV1 the percent predicted FEF 25-75 is used to demonstrate the degree of respiratory illness within the various groups. In terms of FEF25-75 measures of >= 66% of predicted represents normal lung function, 50 - 65% of predicted represents mild obstruction, 35 - 49% of predicted represents moderate obstruction and an FEF25-75 of < 35% of predicted represents severe obstruction.

The mean percent predicted FEF 25-75 at all time periods over all of the relevant groups is less than 35 and indicative of severe small airways obstruction (Tables 5.20-5.22).

Table 5.20: Percent Predicted FEF 25-75 by Control and Intervention Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Control	14.08	± 8.47	14.64	± 11.45	13.85	± 11.21	13.65	± 8.13	15.21	± 8.65
Intervention	15.06	± 10.01	13.07	± 9.06	14.30	± 9.16	13.77	± 9.88	11.97	± 6.33

Table 5.21: Percent Predicted FEF 25-75 by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All IT Users	12.65	± 9.14	11.26	± 8.03	11.26	± 8.03	12.60	± 10.4	13.54	± 6.39
All Non-IT Users	16.52	± 10.37	14.57	± 9.75	12.91	± 8.09	14.65	± 9.65	10.83	± 6.21

Table 5.22: Percent Predicted FEF 25-75 by IT and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
IT Cases	12.67	± 9.99	15.00	± 12.15	12.83	± 8.33	14.00	± 12.23	15.00	± 9.46
Non-IT Cases	15.33	± 14.46	17.17	± 14.25	17.50	± 11.24	13.00	± 11.63	12.83	± 9.45

The mean FEF25-75 scores for all groups indicate that the participants have severe small airways disease and although the scores may vary throughout the participation period all measures indicate significant disease.

5.4.3 Modified Medical Research Council Dyspnoea Scale

The modified Medical Research Council (MRC) Dyspnoea Scale measures perceived respiratory disability. The MRC dyspnoea scale is simple to administer as it allows the patients to indicate the extent to which their breathlessness affects their mobility based upon a grading of 1-5. (Bestall et al., 1999)

Control and Intervention Groups

The MRC dyspnoea scale measurement for the intervention group is slightly lower than that for the control group both at enrolment and at completion indicating slightly less dyspnoea in the intervention group (Table 5.23).

Table 5.23: MRC Dyspnoea Scale by Intervention and Control Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Control	3.82	± 1.08	3.89	± 1.15	3.78	± 1.29	3.80	± 0.99	3.84	± 1.10
Intervention	3.40	± 1.10	3.37	± 1.23	3.27	± 1.17	3.23	± 1.42	3.40	± 1.06

IT users and non-IT users

Within the IT user and non-IT user groups the MRC dyspnoea scale measurement at enrolment and completion was the same (Table 5.24).

Table 5.24: MRC Dyspnoea Scale by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All IT Users	3.40	± 1.19	3.63	± 1.16	3.63	± 1.16	3.39	± 1.58	3.40	± 0.99
All Non-IT Users	3.40	± 1.06	3.17	± 1.27	3.18	± 1.22	3.09	± 1.31	3.40	± 1.14

IT and Non-IT Cases

At enrolment the IT cases had a lower MRC dyspnoea scale measurement than the non-IT cases. At completion the IT cases measure was the same as at enrolment but

the non-IT cases was lower. However, it must be noted that the standard deviation in the non-IT cases is higher than that within the IT group (Table 5.25).

Table 5.25: MRC Dyspnoea Scale by IT and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
IT Cases	3.50	± 1.38	4.17	± 0.75	3.17	± 0.75	3.50	± 1.76	3.50	± 0.55
Non-IT Cases	3.83	± 0.75	3.17	± 1.17	2.83	± 1.47	3.33	± 1.51	3.17	± 0.98

It is evident from these data that participants experience high levels of dyspnoea. The mean MRC dyspnoea scores and subsequent levels of disability correspond to the following grades and statements:

- Grade 3, "I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level"; and
- Grade 4, "I stop for breath after walking 100 yards or after a few minutes on the level"

5.5 Self-reported Survey Scores

Three self-reported surveys were collected at enrolment and then at quarterly intervals throughout the participation period. Further discussion of each of these surveys and the issues of using self-reported data is available in section 2.5.2.

5.5.1 Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale

This 6-item questionnaire is a validated measure of self-efficacy for self-management in people with chronic disease. As the Pathways Home for Respiratory Illness project was aimed at improving participants' self-efficacy for self-management this was a primary outcome measure. A calculated mean of the six items scored is the final Stanford self-efficacy for managing chronic disease score. The effect size for each group has been calculated as described in section 5.1.2 for this survey a positive effect size denotes an improvement.

Control and Intervention Groups

Within the control group there has been minimal change in the self-efficacy for self-management score. This is to be expected as the control group did not experience any change in their care. The intervention group experienced an increase in their self-efficacy for self-management score with an effect size of 0.49 (Table 5.26). This indicates a small to medium positive effect from the intervention.

Table 5.26: Stanford Self-Efficacy Score by Control and Intervention Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Control	5.15	± 2.53	5.19	± 2.40	5.13	± 2.20	5.74	± 2.36	5.10	± 2.26	-0.02
Intervention	5.40	± 2.41	6.25	± 2.34	6.44	± 2.10	5.88	± 2.51	6.57	± 1.68	0.49

IT users and non-IT users

The IT users group has had an increase in their self-efficacy for self-management score and a decrease in the standard deviation indicating an improvement in their self-efficacy for self-management. The effect size of this increase was 0.33 which denotes a small positive effect for this group. The non-IT users group experienced a mean increase of 1.41 on the self-efficacy for self-management score with a corresponding decrease in standard deviation over the course of participation. This provided an effect size of 0.60 which indicates a medium positive effect from the intervention (Table 5.27).

Table 5.27: Stanford Self-Efficacy Score by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
All IT Users	5.60	± 2.56	5.81	± 2.22	5.83	± 2.11	5.54	± 2.42	6.45	± 1.65	0.33
All Non-IT Users	5.28	± 2.35	6.60	± 2.42	6.83	± 2.04	6.14	± 2.60	6.69	± 1.75	0.60

IT and Non-IT Cases

Within the case group the IT cases there was an increase in the self-efficacy for self-management score and a decrease in the standard deviation with an effect size of 0.22 (Table 5.28). This indicates a small positive effect from the intervention. However, the non-IT cases experienced an effect size of 1.49 which indicates a large effect of the intervention upon the participants' self-efficacy for self-management within that group.

This implies that although there is a positive effect for all members within the case group that the use of the online patient diary may in some way inhibit the positive effect of the intervention.

Table 5.28: Stanford Self-Efficacy Score by IT Cases and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
IT Cases	4.89	± 2.72	5.94	± 1.32	5.58	± 1.75	4.50	± 1.91	5.50	± 1.68	0.22
Non-IT Cases	5.22	± 1.10	7.25	± 0.71	6.58	± 1.47	6.53	± 1.38	6.86	± 1.58	1.49

In terms of the development of self-efficacy for self-management the intervention appears to have had a positive effect upon the participants within the intervention group. The online patient diary has weakened the positive effect of the intervention. This is possibly due to the additional learning burden of commencing to use IT.

5.5.2 SF36v2

The SF-36v2 Health Survey is a 36-item short-form survey that measures general health status and is regarded as the standard measure for patient-reported health outcomes assessment. The survey when scored provides a number of summary items;

the physical component summary and the mental component summary are used here (for detail see section 2.5.2.2).

5.5.2.1 Physical Component Summary

The physical component summary (PCS) is a combined score for all sub-scores relating to physical health – physical functioning, role-physical, bodily pain and general health. The effect size for each group has been calculated as described in section 5.1.2 for this survey a positive effect size denotes an improvement.

Control and Intervention Groups

Within the control group there was a slight decrease in the PCS score over the period of participation with a corresponding negative effect size. This is not unexpected as these people did not experience any intervention and it is normal with COPD to experience some decrease in physical function over this period of time. For the intervention group there was an increase in the PCS score (Table 5.29) with an effect size of 0.38 which denotes a small effect from the intervention.

Table 5.29: PCS Score by Control and Intervention

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Control	30.22	± 7.83	29.06	± 9.85	30.79	± 9.93	32.02	± 8.94	29.84	± 7.25	-0.05
Intervention	32.29	± 7.53	33.85	± 9.38	34.55	± 9.83	35.60	± 8.94	35.15	± 10.27	0.38

IT users and non-IT users

Both the IT users and non-IT user groups experienced an increase in their PCS scores, although there was also an increase in the standard deviations for each group (Table 5.30). Each group experienced a positive effect size of 0.42 which is classified at the top of the small effect range.

Table 5.30: PCS Score by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
All IT Users	31.05	± 6.74	31.20	± 9.07	31.52	± 10.07	34.98	± 9.13	33.85	± 10.83	0.42
All Non-IT Users	33.00	± 7.95	35.94	± 9.26	36.34	± 9.46	36.14	± 8.97	36.30	± 9.90	0.42

IT and Non-IT Cases

Both the IT cases and the non-IT cases experienced an increase in the PCS scores over the period of the project (Table 5.31). The IT cases recorded a small positive effect of 0.31 and the non-IT cases experienced a moderate positive effect of 0.52. However, the IT group also experienced a significant increase in the standard deviation from ±3.80 to ±12.68.

Table 5.31: PCS Score by IT and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
IT Cases	27.82	± 3.80	30.86	± 11.03	30.09	± 11.22	30.87	± 10.51	28.99	± 12.68	0.31
Non-IT Cases	32.85	± 9.35	39.55	± 5.21	38.81	± 10.72	36.37	± 8.60	37.76	± 9.21	0.52

In terms of the SF36v2 PCS mean scores all sub-groups within the intervention group experienced increased PCS scores and a small to moderate positive effect indicating an improvement in the way participants evaluate their physical condition.

5.5.2.2 Mental Component Summary

The mental component summary is a combined score for all sub-scores relating to mental health – vitality, social functioning, role-emotional and mental health. The effect size for each group has been calculated as described in section 5.1.2 for this survey a positive effect size denotes an improvement.

Control and Intervention Groups

There was an increase in MCS scores for the control group between enrolment and completion and a small positive effect of 0.29. This is surprising as the control group received usual care only so any change in effect is probably not the result of the project. The intervention group experienced a large increase in MCS scores with a moderate to large positive effect of 0.78 (Table 5.32).

Table 5.32: MCS Score by Control and Intervention Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Control	38.79	± 14.26	45.11	± 14.46	45.19	± 13.57	47.60	± 13.09	42.91	± 15.37	0.29
Intervention	36.08	± 11.24	43.48	± 13.53	44.88	± 13.20	42.39	± 13.28	44.81	± 12.76	0.78

IT users and non-IT users

Both the IT user and non-IT user groups experienced an increase in the mean MCS scores over the period of the project. The IT user group has a large positive effect size of 0.83 and the non-IT user group had a moderate positive effect size of 0.74 (Table 5.33).

Table 5.33: MCS Score by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
All IT Users	36.14	± 10.45	43.31	± 12.72	40.37	± 12.99	39.61	± 12.45	44.83	± 12.91	0.83
All Non-IT Users	36.04	± 11.82	43.62	± 14.42	47.55	± 12.88	44.78	± 13.80	44.79	± 13.00	0.74

IT and Non-IT Cases

Both the IT cases and the non-IT cases experienced increases in their mean MCS scores over the period of the project. The non-IT cases experienced an increase of 9.96 (Table 5.34). There was a moderate positive effect size in the IT cases but a large positive effect size for the non-IT group of 1.27.

Table 5.34: MCS Score by IT and non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
IT Cases	39.45	± 8.46	41.97	± 10.93	39.74	± 9.04	36.16	± 9.50	43.74	± 12.47	0.51
Non-IT Cases	38.64	± 7.85	44.00	± 8.61	47.92	± 8.21	51.54	± 8.52	48.60	± 11.58	1.27

All groups experienced an increase in their mean SF36v2 MCS scores, including the control group. This may be due to the fact that the initial measures were taken whilst participants were hospitalised. However, the size of the effect in the intervention group and subsequent sub-groups is much greater than that in the control group so there is evidence that the intervention has had a positive effect on the MCS scores.

It must be noted that despite the positive changes in most of the SF36v2 scores, both PCS and MCS, all groups scored below 50 which is considered to be the norm for these measures. This corresponds with the clinical perspective that the participants all suffer from moderate to severe COPD.

5.5.3 Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a short and commonly used instrument to measure psychological distress in patients. It has been proven as a psychological screening tool to give meaningful results in clinical group comparisons and in studies with several aspects of disease and quality of life.

5.5.3.1 Anxiety Component

The anxiety component measures the level of anxiety reported by participants with lower scores being an indication of lower anxiety levels. The effect size for each group has been calculated as described in section 5.1.2 for this measure a negative effect size denotes an improvement.

Control and Intervention Groups

The control group has had little change in the anxiety component score from enrolment to completion. In contrast the intervention group experienced a decrease in the anxiety component score with a corresponding small effect size of -0.38 (Table 5.35).

Table 5.35: HADS Anxiety Component by Control and Intervention Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Control	8.76	± 4.97	8.00	± 4.57	7.89	± 5.02	7.74	± 4.71	8.81	± 5.76	0.01
Intervention	9.75	± 4.72	8.67	± 4.46	8.80	± 5.02	8.32	± 4.79	7.94	± 4.33	-0.38

IT users and non-IT users

The IT users group had a decrease in the mean anxiety component score and a small negative effect size. The non-IT group experienced a larger decrease with a small to moderate effect (Table 5.36).

Table 5.36: HADS Anxiety Component by IT and Non-IT User Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
All IT Users	9.70	± 2.72	9.05	± 3.38	10.69	± 3.81	8.88	± 3.61	8.44	± 2.90	-0.27
All Non-IT Users	9.77	± 4.81	8.38	± 4.46	7.68	± 4.87	7.86	± 4.95	7.47	± 4.02	-0.48

IT and Non-IT Cases

Both the IT cases and the non-IT cases experienced a large decrease in their mean anxiety component levels with a decrease of 3.33 in the IT cases and 5.00 in the non-IT cases. Each of these groups experienced large effects from the intervention (Table 5.37).

Table 5.37: HADS Anxiety Component by IT and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
IT Cases	11.33	± 2.88	8.67	± 3.72	10.67	± 1.37	8.67	± 2.16	8.00	± 2.76	-1.16
Non-IT Cases	10.67	± 4.18	6.83	± 1.72	7.83	± 2.48	5.33	± 3.01	5.67	± 3.56	-1.20

At commencement the control group had lower mean anxiety levels than the intervention group as expected there was minimal change in the anxiety levels of the control group over the course of their participation. There was a significant decrease in the anxiety levels of the intervention group over the period of the project. High anxiety levels were experienced in both IT cases and non-IT cases at commencement. By completion of the participation period both the IT cases and the non-IT cases demonstrated a significant decrease in their anxiety levels. For the IT cases there was a large increase in anxiety at the 6 month period the reason for this is not evident from the quantitative data.

5.5.3.2 Depression Component

The depression component measures the level of depression reported by participants with lower scores being an indication of lower anxiety levels. The effect size for each group has been calculated as described in section 5.1.2 for this measure a negative effect size denotes an improvement.

Control and Intervention Groups

There has been a slight increase in the depression component in the control group over the course of the project. The intervention group experienced a small decrease in the depression component of 1.41 and a small effect size of -0.35 (Table 5.38).

Table 5.38: HADS Depression Component by Control and Intervention Groups

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Control	7.29	± 3.58	6.72	± 3.88	6.82	± 3.70	6.79	± 4.12	7.71	± 4.92	0.12
Intervention	6.93	± 3.98	6.49	± 3.99	5.89	± 3.94	5.82	± 4.28	5.52	± 3.41	-0.35

IT users and non-IT users

The IT users had a low depression component score at enrolment and there was only a very small decrease in the score over the duration of the project of 0.05. The non-IT

user group had a decrease of 2.00 in the mean depression component score over the duration of the project, with a small to moderate effect size of -0.47 (Table 5.39).

Table 5.39: HADS Depression Component by IT Users and Non-IT Users

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
All IT Users	5.05	± 2.72	6.74	± 3.38	7.00	± 3.81	5.76	± 3.61	5.00	± 2.90	-0.02
All Non-IT Users	8.00	± 4.21	6.29	± 4.48	5.23	± 3.95	5.86	± 4.84	6.00	± 3.86	-0.47

IT and Non-IT Cases

The IT cases demonstrated an increase in the mean depression component score over the duration of the project resulting in a small increased effect size. In contrast the non-IT cases demonstrate a large decrease in the depression component scores over the duration of the project (Table 5.40).

Table 5.40: HADS Depression Component by IT and Non-IT Cases

	Enrolment		3 Months		6 Months		9 Months		12 Months		Effect Size
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
IT Cases	5.17	± 2.93	6.50	± 2.74	7.50	± 3.78	7.00	± 2.76	5.83	± 1.47	0.23
Non-IT Cases	7.33	± 3.61	4.00	± 1.41	3.83	± 2.56	3.83	± 3.92	3.83	± 1.94	-0.97

The depression levels expressed through the data demonstrated normal ranges for all groups at all measure points with the single exception of the Non-IT users group at commencement. This group had a mean score of 8.00 which is at the low end of borderline psychological morbidity. Improvement in depression levels was experienced in all intervention sub-groups with the exception of the IT cases where there was a small increase. This effect could be due to the small number of cases involved.

5.6 Symptom Monitoring Diary Usage

The symptom monitoring diary was provided to all participants in the intervention group. The intention of the intervention was that the diary would be completed daily. The actual diary use was much lower than anticipated, with a total of 11,477 diary entries being received over the duration of the project. These data have been analysed in terms of the sub-groups (Table 5.41).

Table 5.41: Symptom Monitoring Diary Usage

	All Non-IT Users	All IT Users	Non-IT cases	IT Cases
Total	6255	5206	1859	1703
Mean	178.71	260.30	309.83	283.83
Range	0-372	59-380	189-349	83-376

As is evident above the diary usage was unpredictable. These data are difficult to interpret due to the fact that people commenced the trial at different times over a two year period and many of those who commenced did not complete their twelve month participation period.

Although the All IT Users group displays a higher mean usage than the All Non-IT Users group this is not consistent with the IT Cases group, where the Non-IT Cases

group has a higher mean use. The diary usage will be further explored in Chapters 6 and 7.

5.7 Reflections

This chapter has provided analysis of the quantitative data collected through the Pathways Home for Respiratory Illness Project. The data has been analysed in relation to a number of different groupings that relate to this research and in particular the research question and objectives presented in section 5.1 above.

The data has revealed a number of findings which will be explored in more detail in future chapters.

- The online patient diary is more likely to be adopted by females in the younger age group.
- Education level has no obvious impact upon decision to use online patient diary.
- Online patient diary use has an impact upon withdrawal rates
- Self-efficacy for self-management scores were improved through the intervention but the effect was dampened when the online patient diary was introduced.
- The intervention appeared to improve the SF36v2 physical component summary scores in all groups. Interestingly there was a difference between the case groups that did not exist between the all IT Users and All Non-IT Users.
- The SF36v2 mental component summary scores all improved but there was significant difference in the size of the improvement between the IT Cases and the Non-IT Cases.
- There was a decrease in the anxiety levels of intervention participants over the course of the intervention. For the IT cases there was a large increase in anxiety at the 6 month period.
- There was a slight increase in the depression levels in the IT Case group; however, this did not reach above the normal level.

For many of these results the reason for them is not evident from the quantitative data. There are some results which require examination through qualitative methods and some that could be best explained through individual experiences or the knowledge of the impact of the individual experiences upon the groups. This is particularly evident for deviations in results in the case groups and these will be explored in more detail in subsequent chapters.

In addition, the clinical results raise questions regarding the appropriate handling of data and selection of measurements. There is no doubt that spirometry data is useful both at an individual and population level. However, within this trial the use of these measures is surrounded by a number of variables, which have not been, and cannot be, addressed using descriptive statistics. Although these data were collected at regular periods they do not account for some participants' inability, due to the severity of their illness, to perform the spirometry test at certain points. Thus, although this analysis provides some indication of changes in condition a thorough statistical

analysis may reveal more comprehensive results. The individual clinical scores will be explored in more detail within the context of the individuals' experiences of the trial in chapter 7.

The next chapter will address the data in relation to the first research objective of the second research question

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO1 To qualitatively explore the impact of the online patient diary.

Chapter 6 provides an in-depth discussion of the coding process involved in the analysis of the triad interviews. The core categories are explored in detail and the relationships between the core categories are identified. Finally a cross group analysis of the triad interview data is presented to determine similarities and differences between the two groups included in the research, those who adopted the online patient diary and those who did not.

Chapter 6 Triad Interview Analysis

> When the evidence shows "effectiveness" – i.e., the intervention does more good than harm – in a group of patients, we should not assume the result is equally valid for all individuals. The process of individualisation remains at the heart of clinical practice and is the primary task of the clinician (Muir Gray, 2004b, p. 1468)

6.1 Introduction

This chapter provides details of the results of the triad interview analysis.

- Section 6.2 briefly reflects upon the method by which the axial codes and core categories were derived and then provides a detailed description of the core categories and axial codes contained within them through a cross case analysis.
- Section 6.3 explains the relationships between the core categories.
- Section 6.4 provides a cross group analysis which investigates the similarities and differences between the IT and Non-IT groups.
- Section 6.5 provides reflections upon the contents of the chapter.

6.2 Interview Data Analysis – Stage 1

This section describes in detail the first iteration of the interview data analysis. The process is discussed firstly through the application of the coding to the data across the twelve cases (Section 6.2.1). The four core categories that emerged from coding the triad interviews (Section 6.2.2) and their related axial codes are discussed.

The primary purpose of this phase of the data analysis was to obtain insights into the nature of the participants' experiences with an online patient diary within a mentored self-management programme through the use of cross group and within group analysis. This was to align with the first research objective of the second research question.

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO1 To qualitatively explore the impact of the online patient diary.

6.2.1 Overview of Coding Process

Coding was employed to systematically reduce the data into a more manageable form, using the thirty-six interview transcripts, one from each member of the participants' care triad. Open coding was conducted on each of the thirty-six transcripts in accordance with the process described in Section 4.6.2.1.

Once open coding had been conducted on each transcript, the next stage involved systematically organising the codes and applying the technique of constant comparison to arrive at axial codes for each interview (the process is described in

detail in Section 4.6.2.1). At the completion of this process 45 axial codes were identified.

The next step was to combine the axial codes from the triad interviews for each case and then to review the axial codes within the triad to decrease the number where there was similarity. This was undertaken through comparing the axial codes and the underlying open codes to determine points of similarity or overlap of the axial codes assigned at the individual interview level. Through this iterative process the number of axial codes was reduced from 45 to 26 codes that were common within and across all twelve triads. Through this reviewing process an intricate web of relationships between and within the codes emerged.

Selective coding was subsequently employed to identify central or core categories (Section 4.6.2.1). The primary research question and objective were drawn upon to help guide selective coding. Selective coding is "the process of selecting the central or core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development" (Strauss & Corbin, 1990, p. 119). All other core codes derived from that axial coding process must be related to the focal core code, either directly or indirectly. The resulting axial codes and core categories (as described in detail in section 6.2.2) were used in both the cross group analysis (section 6.3) and the individual case studies (Chapter 7).

Four core categories appeared to have relevance to the implicit nature of participants' experiences within the mentored self-management programme and will be discussed in detail in the next section.

6.2.2 Core Categories

This section provides a detailed description of the four core categories, which emerged from the coding process described in section 4.6.2.1:

- Personal Experience (Section 6.2.2.1);
- Outcome (Section 6.2.2.2);
- Project Experience (Section 6.2.2.3); and
- Technology Experience (Section 6.2.2.4).

The following are descriptions of each of the four core categories and the relationships within the core categories. Also there is discussion of potential relationships between the core categories. The purpose is to explain the derivation of the core categories.

6.2.2.1 Personal Experience

This section describes the core category PERSONAL EXPERIENCE. This category encompasses the way the different interviewees within the triads describe or reflect upon the many facets of Personal Experience in relation to each case. In this section the Personal Experience is described in terms of many impacting factors, or the axial codes as derived for the coding process.

Initially this category was two separate categories DISEASE EXPERIENCE and PERSONAL EXPERIENCE. However, after reflection upon the aims of the Pathways

Home Project and the World Health Organisation's definition of health that suggests that health is:

> a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities (WHO, 1989).

It was determined that combining these two categories gave a more holistic view of the codes in respect to people's life experiences rather than creating a false divide between PERSONAL EXPERIENCE and DISEASE EXPERIENCE. Given that the Pathways Home Project is a health behaviour intervention and this was the focus of the interviews the category PERSONAL EXPERIENCE has a focus on personal experiences as they relate to health.

There are six interrelated codes within this category with the central code being health behaviour, the relationships between the codes are discussed below and graphically represented in Figure 6.1. The codes are:

- *HEALTH SYSTEM* relates to how the health system as a whole impacts upon their care.
- *HEALTH UNDERSTANDING* relates to the person's understanding of their illness specifically and in relation to their health generally.
- *SUPPORT MECHANISMS* relates to the various support mechanisms discussed by participants as being important to their ability to maintain their lifestyle.
- *HEALTH GENERAL* relates to how participants discuss their health issues.
- *HEALTH BEHAVIOUR* relates to how interviewees describe the cases' behaviours both in relation to their COPD and any other health related issues.
- *HEALTH IMPACT* relates to the way in which the illness impacts upon participants and their lifestyle.

The code *HEALTH SYSTEM* influences *HEALTH UNDERSTANDING* as access to health care providers is an essential part of gaining accurate and relevant health information which is essential to *HEALTH UNDERSTANDING*. *HEALTH SYSTEM* also influences *SUPPORT MECHANISMS* as frequently *HEALTH SYSTEM* acts as a gatekeeper to access to *SUPPORT MECHANISMS*. Thus without access to *HEALTH SYSTEM* there is limited access to the formal *SUPPORT MECHANISMS*. Finally *HEALTH SYSTEM* influences *HEALTH BEHAVIOURS* in that recommendations for changes to *HEALTH BEHAVIOUR* are often mediated through the *HEALTH SYSTEM*.

HEALTH UNDERSTANDING, in addition to the relationship with the *HEALTH SYSTEM*, also is influenced by *HEALTH GENERAL*. If *HEALTH GENERAL* is poor or complex then the ability to influence/improve *HEALTH UNDERSTANDING* is low. *HEALTH UNDERSTANDING* impacts upon *HEALTH BEHAVIOUR* as to employ beneficial *HEALTH BEHAVIOURS* it is necessary to have a degree of *HEALTH UNDERSTANDING*.

HEALTH GENERAL influences *HEALTH BEHAVIOUR* as it is difficult to influence/alter *HEALTH BEHAVIOUR* in situations where *HEALTH GENERAL* is poor or complex. *SUPPORT MECHANISMS* also influence *HEALTH BEHAVIOUR* as they are required to enable and sustain alterations in *HEALTH BEHAVIOUR*.

Finally *HEALTH BEHAVIOUR* both influences and is influenced by *HEALTH IMPACT*. Where a negative *HEALTH IMPACT* is experienced it can negatively influence *HEALTH BEHAVIOUR* or a positive *HEALTH IMPACT* can positively influence *HEALTH BEHAVIOUR*.

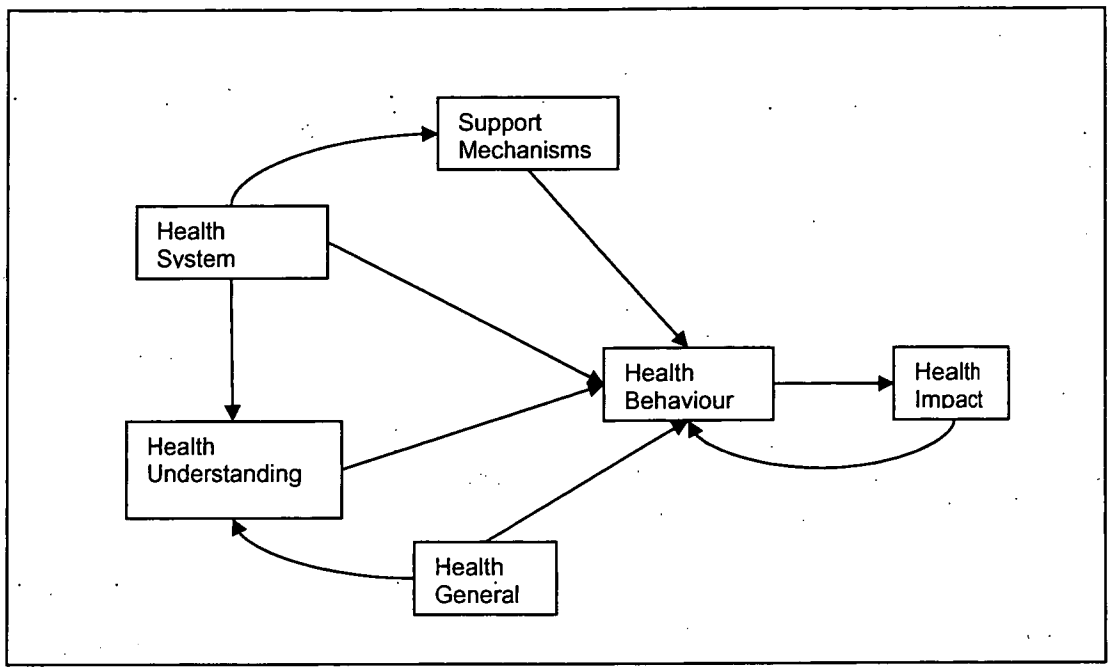

Figure 6.1: Code Relationships within Category Personal Experience

Each of the axial codes is discussed below using excerpts from the interview transcripts to further illustrate the codes and their relationships within this category.

HEALTH BEHAVIOUR

This code is associated with how interviewees describe the health related behaviours both in relation to the participant's COPD and any other health related issues. *HEALTH BEHAVIOUR* is an important factor in how a person experiences their disease process and can have a significant impact upon how and why they may engage with the intervention.

Participants' attempts at changing their health related behaviours require the support of family and friends. Both Beryl and Constance attempted to change their health related behaviours by stopping smoking but suffered from a lack of support in making these changes and so this compromised their ability to change.

> She's still down to just her two cigarettes a day and refuses to give up anymore and I'm quite happy with those and said you've done a brilliant job by cutting down and if she wants two cigarettes a day as a reward or as a calmer or a relax well or whatever then she's doing really well, especially as her husband is still smoking (Beryl's Mentor).

> I've been trying (to give up smoking) for nearly a week I went with only having about three a day but this Tim (neighbour) he will come in and light up when I'm not smoking (Constance).

Case I experienced a change of housing which increased his stress levels and resulted in reversion to old health behaviours that are potentially detrimental to his health.

> Well at the moment, and I've already told my Doctor last week she says well that's what I'm 'ere for. I started smoking again ..... Well you know it's only because I kicked myself because I'd been off it for years (Ivan).

Health behaviour is also affected by the way in which participants perceive the patient role within health care. Within the group of participant interviewees there is a tendency towards the traditional passive patient model where compliance with the doctor's orders is the role they play. This is evident in cases A, C, D, E, F and G and this can potentially be at odds with the process of self-management.

For example, for Constance, compliance with the doctor's prescribed treatment is important even when it is proving detrimental to her health.

> I said you can't keep going like this Constance you know you've really got to go back and be reviewed because you know you are just going to crash and burn if you're not eating, can't drink and you are vomiting all the time then you are just going to end up really coming unstuck but she would "oh No I'll just try it for another couple of days and see" you know so she was really trying to be compliant (Constance's Mentor).

Others go to the doctor when they feel unwell but also see that it is the doctor's role to get them better. This attitude may impact upon the participant's ability to accept and adopt self-management practices.

> No oh not really I just go....I mean if I'm well I'm well and if I'm not I'm not you know I mean that's the way I look at it you know. I mean the doctors have kept me alive one way or another and I'm grateful for them (Francine).

> I won't go to a doctor unless I flamin' have to (Gaye).

It was apparent from the interview data that some participants were not proactive in looking after their own health. Kerry became very ill prior to her diagnosis, and subsequent enrolment in the Pathways Project, because she was very active but neglected her own health while looking after her invalid husband. Cases C, D, F, G and I also demonstrated a tendency to neglect their own health prior to enrolment.

> So yeah she was newly diagnosed and she wasn't looking after herself either wasn't drinking well, wasn't eating well and sole carer for her husband but has carers in and was also working evenings Kerry's Mentor).

There was evidence from the interviews that some participants were more proactive in relation to improving their health through lifestyle management. Three cases attend a gym and undertake physical exercise as part of their health behaviour. To these people this is an extremely important part of their lives and an important element to the maintenance of their health. It must be noted that this gym attendance was not initiated through the project although it was encouraged by the mentors.

> [I]f it's not possible to get there I feel as if half my legs got cut off sort of thing because even though sometimes I can't put in an appearance, if I put in an appearance even just doing the arm pedals or something I feel like I've achieved something and Pathways is similar. Every little bit helps and I've followed that philosophy for years and I do find that everything that I attempt you know I can absorb and it has helped (Janice).

It is evident from the interviews that participants demonstrate differing levels of health related behaviour, with many of them compromising their health for other people. They also appear to devolve responsibility for their health to health care

professionals rather than viewing their care as a partnership or even any level of personal responsibility. These traits may be due to demographic, social or clinical influences and this will be explored in more detail in Chapter 7.

HEALTH GENERAL

The code *HEALTH GENERAL* is used to describe how participants discuss their health issues. Many of these participants have other chronic conditions as well as their COPD. Within the analysis it is evident that these health issues have impacted upon the person's COPD experience even though they may not be directly related. This is evident from the following quotes.

> As for it helping me to look after my health I don't think that it will ever change anything because I've got to be so careful with my diabetic. My bad heart, my bad lungs, my rheumatism. I just have to be so careful of what I do, what I eat and when I do it. But as to whether you people can ever help me or help anybody else with what I'm doing is I'm saying I don't think it ever will. It could do you know more about that than me probably. But (pause) I wish it would but I don't think that it could (Edward).

Other participants could identify where an apparently unrelated illness has had detrimental impact upon their overall health and can even mimic the symptoms of the COPD. In a number of cases this led to misdiagnosis at the time of subsequent hospital admissions. This was particularly evident in cases C and E.

Constance had three hospital admissions that were initially attributed to exacerbations of her COPD but were finally diagnosed as gastro-intestinal problems.

> I spent weeks and weeks just laying on that couch I'd go to the doctors and they'd say a chest infection go into hospital and they had me on that many antibiotics but it wasn't a chest infection and ....the last time I was coming home Dr X said I could come home and Amy, one of the registrars there, and I just climbed back into be I just felt so ill and she looked at me and she said to the nurse "Constance's not going home today she's staying." and that's when she arranged to have this down here (endoscopy) because I'd been telling her I'd used my bowels that morning Oh smell and it was black and straight away that's when she had the lights and thinks I might be having a small bleed inside (Constance).

Edward had similar experiences where his hospitalisations were attributed to COPD but were in fact eventually discovered to be a bacterial growth within his pacemaker wires.

> You see these trips that I have had to hospital recently since March 28th. After the first episode they never ever completely cured me of what they said was wrong with me now I am quite convinced that I did not have bloody pneumonia, 'cause I know what pneumonia is. But that's what they said they said I had pneumonia and my heart was playing up. But my heart was playing up and racing because I couldn't breathe properly because I was huffing and puffing (Edward).

With those participants who have had COPD for a long period of time or have experienced a number of acute exacerbations the participants themselves can often identify the difference between an exacerbation of their COPD and other illnesses with similar symptoms. Alternatively they can identify where treatment for another condition impacts upon their COPD.

> I can't have a drink any more 'cos my stomach won't handle it with this reflux which has been so bad lately That's half my breathing problem. I just can't get me breath and it's not a chest infection, it is reflux (Constance).

In the case of Janice it is evident that she can see the relation ships between her different illnesses and how they may impact upon one another. This may be due to Janice's long history of illness and that she was a trained nurse, although she has not practiced for thirty years.

> I'm on diabetic medication I'm on fluid tablets and I'm on antibiotics and then you see you have and well with the shingles I had this whiz bang bombshell of a thing you know which they give you within 72 hours well all of those are impacting on the condition and throwing them out of kilter. So it's not necessarily that you are feeling so bad purely from the shingles, the other are exacerbation of other conditions which are just out of control. (Janice).

Interestingly the mentors and the research assistant failed to directly address the issue of these co-morbidity effects in any detail during the interviews but in discussions outside the interviews they did. This may be due to the interview questions asked.

There is evidence from the interviews that there is a wide range of other conditions that can impact upon a persons' ability to manage their condition. Some people, most frequently those with long experience of their condition, can recognise these interactions and adjust for them.

HEALTH IMPACT

The code *HEALTH IMPACT* describes the way in which their illness impacts upon them and their lifestyle. Most participants discussed to some degree the physical impact of their COPD although those who were closer to their initial diagnosis or had less severe COPD symptoms tended to de-emphasise these effects.

The impact upon participant's ability to carry out daily tasks is evident and people have to adjust to operate within their limitations. This can be a very difficult adjustment for some to make.

> If I go out and dig the garden I've got to stop every ten minutes and stand up because I get sort of not the cramp and I seem to lose my capacity for breath and stand up and take a few deep breaths and take a look around and then I can go for a bit more and I can and I go for another ten or fifteen minutes and then I have got to stop. I'll always be like that and that will never improve (Edward).

> And so I think she's pretty good at ... being realistic about what she's capable of and plods along and gets her housework done and you know makes her meals and has relatives come and stay, young, in many cases young people (Gaye's Mentor).

> It's very hard to tell people when they are assessing you and then you get home and I'd probably sit in the chair and go to sleep and then not be able to breathe for an hour. You know cough and splurt it and splutter it and stuff. But you know I don't know what it is but you can still function very well (Janice).

Harold demonstrates the frustration and difficult path to adaptation of lifestyle that is required with the onset of this disease. He suffered a severe chest infection, which led to his diagnosis, and this resulted in a rapid deterioration in his condition. He went from leading a very active life to being unable to walk to the letter box.

> Couldn't believe it. I'm really; you can see that I'm affected by it. I mean I was a trans-Derwent swimmer. I could swim the length of the Olympic pool underwater and hold my breath for over four minutes and now listen to me. I have a job to take the rubbish tin outside the damn door here (Harold).
>
> [I]t was a major change in lifestyle for this gentleman. He used to do a lot of boating, do a lot of things with his friends and do a lot of socialising and it's been dramatic change and a major change for him. So there has been a certain level of degree of acceptance and frustration on his part as well (Harold's Mentor).

Some participants appeared to reach the point where their lives were defined by their illness and the limitations that it placed upon them. Constance is the most extreme example of this:

> I just couldn't be bothered arguing with anyone these days because it just takes too much out of me so it is better just to say look just leave (Constance).
>
> I think that with Constance she's been at that survival phase really for a while and just getting by and that's it (Constance's Mentor).
>
> Well I just haven't got the breath to get out and I mean even to go into the hospital now if I've got to go up to the specialist clinic my daughter's got to get a wheelchair and take me up I just couldn't walk that distance now. I can't even do my own shopping now so it is no good going on an action plan when you can't get out and do it (Constance).

Other participants have decided that it is important to just get on with life and live the best and most active life that is possible.

> So I can't see any sense in sitting feeling woe is me and everything else. It is what it is. What's being done is being done and that's about all that can be done. So you grin and bear it and you make the most of what's there and that's all that I can do (Janice).

Some participants, for example Constance, are fatalistic about their illness and this discourages change.

> But I've been told that its (smoking) going to kill me in the finish anyway so. I don't know its only thing I've got left that ..(pause) .. can't have a drink any more 'cos my stomach won't handle it with this reflux which has been so bad lately (Constance)

The limitations can have major implications for family members as well. Janice describes a recent outing with her granddaughter.

> But yesterday <X> came for instance, my little granddaughter and they've been away and <daughter and son-in-law> called in and they said <X> would like to stay with you for an hour, do you feel up to it? I said yeah lovely. Because she comes and in she looks after me she thinks which she does at times. So we sat here for a little while and she was, and I said would you like to go down and have some lunch? And she was in her element there so she got the scooter ready for me and got the oxygen in she knows, she's only nine but she knows how to set it up and everything and she stood on the back of it and off we went down and had a sandwich and that was the first time I'd been out of that for oh over a week and I hadn't, I didn't have the confidence I wouldn't have been able to do it on my own but even at nine years of age there was just enough assistance there to open and close doors, check and put the oxygen in and things like that and we're off and it was great (Janice).

Gaye describes the situation that she faced with her daughter being too frightened to have her at her home for Christmas celebrations.

> I was going out for Christmas day but me daughter rang me up that night and said she'd had a (pause) have it out here bring the Christmas dinner come down and have it out for seven o'clock, cooked me breakfast and then bring all the other Christmas stuff down all chopped up for me to eat down here. And the reason that she did that because she was frightened of taking this machine (oxygen cylinder) up and she said if it might get real hot I might collapse or something and she'd be frightened and might have to get an ambulance (Gaye).

All participants except Participant A discussed the issue of limitations placed upon them by their illness. Participant A appeared to have very little understanding of his illness and also had few symptoms on a day to day basis which would impact upon him. Any limitations he accredited to his "sore knees" and not his COPD.

> [Y]ou'd have the odd day when you didn't feel so good like anybody does but most of the time I feel reasonable. It hurts too much to walk and try and do things, so I've got rid of all the garden, that was all garden right down there down past that far tree (Albert).
>
> It was always his legs (Albert's RA).
>
> But he didn't think that he had too much dramatically wrong with him. Anything that was wrong with him whether it be his COPD or his legs or his arthritic type of stuff it was to do with age (Albert's Mentor).

The interview analysis demonstrates that COPD has a huge impact upon the lifestyle of sufferers and their families. The participants find different ways to deal with the limitations ranging from denial, through acceptance and modification of lifestyle to a fatalistic view of inevitable death. Interestingly these responses are not necessarily associated with the severity of the current symptoms.

HEALTH SYSTEM

This code describes how the health system as a whole impacts upon their care. Although this code was not expressed by many of the participants it is considered to be an important factor and influence in a person's disease experience. Where participants did discuss the impact of the health system it was often evident that in some manner the health system had impacted upon their health.

Poor communication, particularly between the primary and tertiary health sectors was one of the main ways in which the health system impacted upon participants. This is evident from the following quotes.

> He (GP) rang up (the hospital) about four or five times and I went crook at the sister and with the doctor whenever it was last week when I was in there and I told her he wasn't happy because he hadn't received it (discharge summary). She opened my folder and said "there it is there, I wrote it out, it should have been sent". Well I said that he hasn't got it (Edward).

This lack of communication leads to poorly co-ordinated care and people do not receive the information that is relevant to their care.

> That's because when I got down to it he's actually been he'd actually been an admission to hospital for heart things and I mean it is a real failing here. It's

> not you know they get for him for one thing and that's it. No-one else looks at them and talks to them (Edward's RA).

A further example of this is the confusion about Beryl's medications. This medication for her arthritis has been found to exacerbate her respiratory condition and so her respiratory physician has recommended that she cease the drug but this information has not been effectively communicated to her GP.

> I've got to go back to him shortly so I'm just going to ask him to give me a letter to take to her (Beryl).

Also the constant need to repeat information can be problematic to participants particularly those with multiple co-morbidities.

> And in this day and age with so many change overs of doctors and every time you go into Cas (Emergency Department). And you can sit there and I'm thinking of taking a tape recorder. 'Cause one day I was in there with some med. students and I think I told them my history six times to six different people. And I thought you know no this is getting a bit past a joke now and it makes you feel, it does make you feel it gives you confidence in the system and as I said because I've been involved with it for so long I've seen a lot of staff come and go (Janice).

From the interviews it is evident that the health system and in particular poor communication within the various levels of the health system, leads to considerable difficulties and poorly co-ordination of care for people with COPD.

HEALTH UNDERSTANDING

HEALTH UNDERSTANDING relates to the person's understanding of their illness specifically and in relation to their health generally. This includes the perceptions of those members of the care triad interviewed in relation to the participant's understanding of their health.

From the interviews it is evident that there are different degrees of understanding of their health demonstrated by the participants. These ranged from very limited understanding to extremely good understanding. This was confirmed by the mentors and research assistant but there is no evidence that the different levels of understanding altered the mentoring process.

> I know I'm getting a chest infection I'll go to the doctor there is no good of me waiting until I get too sick and then I end up back in hospital (Constance).

> She was a very nice lady quite chatty and when I asked her about all her relievers and all this sort of condition, the lung condition the one she knew all that too, and she's really fairly you know, fairly clued to it really. She seemed to know about it (Doreen's Mentor).

Mr E demonstrates his understanding of his health in discussing his plans to lose weight and the potential this has to influence his health generally. He also demonstrates and understanding of the severity of his COPD and the eventual outcome.

> I'm going to try it and I am determined to try it and I think that if I can get that off I will breathe a lot better and my health will be a lot better. And my knee will be a lot better. I'll probably feel a hell of a lot better and I feel good now it's just that this bloody knee and well both my knees for that matter are and stopping me from doing anything. I've got a wall to paint out there but I can't

> get up the bloody ladder. Those are the things that annoy me and I don't worry about the bloody breathing part of it that will never be the same or get any better, and I've had too many doctors tell me that it will never improve because of the clogged up, oh they give it a name, tubes that goes into the lungs (Edward)

Francine has obviously less understanding of her illness as she is even unaware of the actual diagnosis. Despite this her mentor considers that she does have some understanding of her illness and the eventual course of the illness.

> Well, I went to the doctor on the 10 of December (2005) and I ended up in the hospital but doctor X thought that I might have had asthma or emphysema but I gave up smoking so he said no I was on the verge of it so I don't know if that is what it is or what it is you know (Francine).

> And she does understand that it's going to be a long term thing and not going to clear up overnight (Francine's Mentor).

For some participants it was quite evident that the mentors and research assistant had conflicting opinions of their understanding of their illness. For example, the mentor for Case I expressed doubts that the participant really understands his illness.

> I doubt if he's got a full understanding no, I really question to this day whether he has a full understanding of his disease process. No. No well he knows his lungs are buggered and he couldn't walk (Ivan's Mentor).

Interview analysis clearly demonstrated that Janice understands the severity and trajectory of her illness. She also demonstrates an understanding that when she has an exacerbation her condition is unlikely to return to the same level of health as prior to the exacerbation.

> So, that was another bit of a downward trend and this I have no doubt is going to be another downward trend with my level of fitness. I can feel it and even though I know I try and keep it going and that's as much as I can within my capabilities there which is certainly not a step upwards. It's a step backwards from you know what I mean (Janice).

It is evident from the interviews that participants have a very wide range of understanding of their illness. To some degree this relates to their situation within the trajectory of their disease, however, this does not completely account for the variance. There may be some relationship between health understanding and demographic variables and this will be explored in Chapter 7.

SUPPORT MECHANISMS

The code *SUPPORT MECHANISMS* relates to the various means of support discussed by participants as being important to their ability to maintain their lifestyle. Family and friends were noted to be key support mechanisms for the participants. The degree of interaction with family and friends varied between participants as did the supportiveness of these interactions.

> She'd got quite a supportive family around her so she didn't bother doing much with the housework because there was somebody to look after her first off when she came out of the hospital (Doreen's Mentor).

The importance of having a purpose to your day or a reason to get up was emphasised by participants C, D, J, L and K. For these participants membership of a support

group, whether social or health related, was an important factor in maintaining some "normality".

> The most important thing I've discovered is if you're on your own in your home you have to have a purpose for the day and the best purpose for the day is out. Now you can either go out to a social group, you can go out to playing cards, you can go out on a ritual and go for a walk or go for a ride but either way you've got to have a purpose to your week and your day because otherwise you're not meeting people. If you're out at work that's fine. You're going and you're interacting with people but unless you do that you don't interact (Janice).

In Case J involvement with health support group was a major factor for the participant and also provided her with additional understanding of her illness. The benefits of involvement with the support group was reflected in both her comments and those of the mentor and research assistant.

> Well she's very involved with the Lung Net isn't she, so well I think probably well that's another reason that her understanding is so good she'll be out there to promote a better sort of health for people like her you know to actually be able to cope with how they are sickness wise and how they can improve their health and she's trying to be a advocate for them and trying to actually do set up that support system and she's done it hasn't she? (Janice's Mentor)

From analysis of the interviews relating to Case J it is evident that the medical professionals are also seeing the benefits of the support groups. Other participants did not indicate this and so it is possible that this is specific to Case J because of the high level of involvement she has with COPD support and also with the medical profession.

> The doctors have been spurring them on and all I did was distribute the pamphlets saying do you want a support group for the Lung Net, a cup of coffee, a cup of tea,...friends and relatives want to know more. Just come along and have a cup of coffee and it's amazing lots to do with the oxygen and their drugs and what people do here, there and everywhere and it's been a consistent lot coming straight through which is good (Janice).

Through the interview analysis it is evident that support mechanisms are extremely important to maintaining a degree of normality in the participants' lifestyles. There is a range of support mechanisms employed and they may be formal or informal. For most participants the family forms the core of the support mechanism aided by their health care professionals, most commonly their GP. Some participants engage with formal health focussed support groups. It appears possible that more formal support mechanisms are utilised by people who live alone and also those with more experience with their illness. This will be explored in section 8.6.4.

The axial codes included within the core category PERSONAL EXPERIENCE are important in relation to this research as these represent key areas that the triad interview participants have discussed which influence a participant's experiences within the project and in relation to their illness. As is evident from the analysis of these codes within the interviews there is a wide variation between the participants' life experiences, illness experiences and the methods they use to cope with the changes to their lifestyle as a result of their illness.

6.2.2.2 Outcome

This section describes the core category OUTCOME. This category relates to outcomes, changes in behaviour or attitudes that participants, mentors or the research assistant consider are attributable to participation in the Pathways Home Project. This category is closely associated with the project aims.

The category OUTCOME has five underlying and inter-related axial codes. The codes and their relationships are discussed below and graphically represented in Figure 6.2.

- *DIARY OUTCOME* relates to what the cases have gained/changed from use of the symptom monitoring diary and the longitudinal feedback.
- *HEALTH KNOWLEDGE* relates to whether and how knowledge about their COPD was altered by participation in the project.
- *PROJECT IMPACT* relates to changes to participant's lives as a result of their involvement in the project.
- *SELF-MANAGEMENT BEHAVIOUR* ways in which participants display self-management related behaviours as a result of their involvement in the project.
- *SELF-MANAGEMENT KNOWLEDGE* relates to a wider perspective on the concept of self-management and the need for a balanced approach

HEALTH KNOWLEDGE is influenced by, but also influences *PROJECT IMPACT*. As there is an increase in *HEALTH KNOWLEDGE* an increase in *PROJECT IMPACT* is frequently experienced. Also as learnings from other areas, both within the project and externally, influence *PROJECT IMPACT* this can in turn feed back to *HEALTH KNOWLEDGE*.

HEALTH KNOWLEDGE has a reciprocal relationship with *SELF-MANAGEMENT BEHAVIOUR* as increased *HEALTH KNOWLEDGE* can provide a stimulus for increased *SELF-MANAGEMENT BEHAVIOUR* and vice versa.

DIARY OUTCOME influences *SELF-MANAGEMENT BEHAVIOUR* as the understanding gained through a positive *DIARY OUTCOME* can also lead to alterations in *SELF-MANAGEMENT BEHAVIOUR*. There is also evidence that *SELF-MANAGEMENT BEHAVIOUR* influences *DIARY OUTCOME*, this can occur directly or mediated through *PROJECT IMPACT*. *DIARY OUTCOME* influences *PROJECT IMPACT* as low *DIARY OUTCOME* appears to relate to decreased *PROJECT IMPACT*.

SELF-MANAGEMENT BEHAVIOUR influences and is influenced by *PROJECT IMPACT* as improvement in *SELF-MANAGEMENT BEHAVIOUR* leads to changes in *PROJECT IMPACT* and vice versa.

SELF-MANAGEMENT KNOWLEDGE is not evident without *SELF-MANAGEMENT BEHAVIOUR* and is also influenced by *PROJECT IMPACT*.

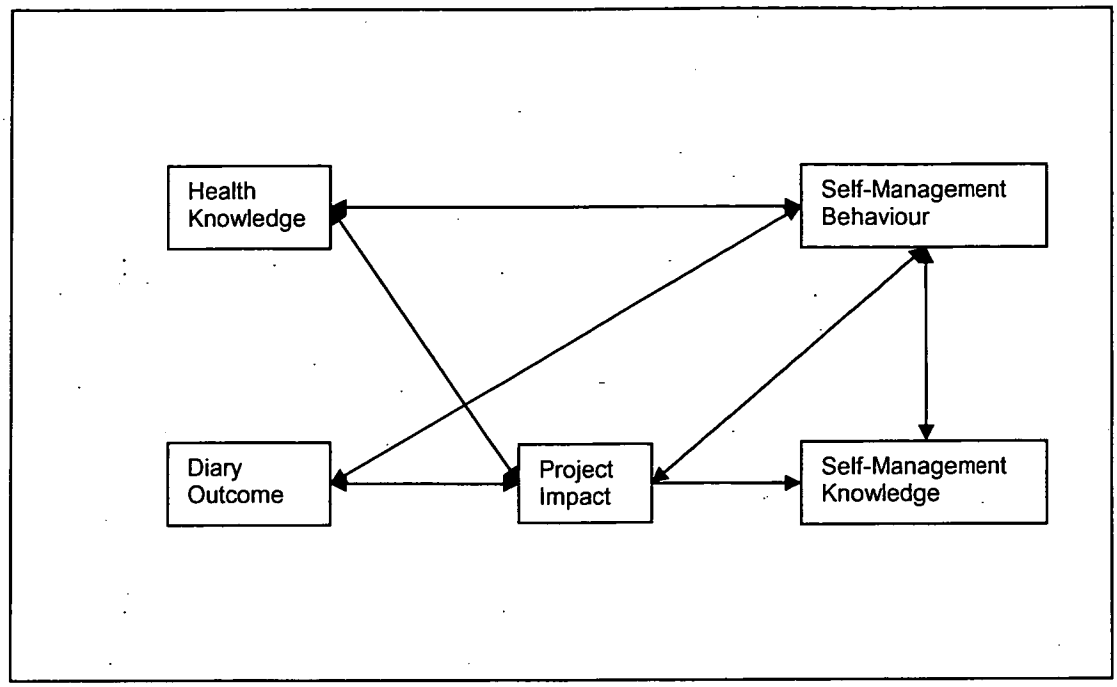

Figure 6.2: Code Relationships within Category Outcome

Each of the axial codes is discussed below using excerpts from the interview transcripts to further illustrate the codes and their relationships within this category.

DIARY OUTCOME

The axial code *DIARY OUTCOME* relates to what the cases have gained/changed from use of the symptom monitoring diary and the longitudinal feedback. Cases A, C, E, F, G, H, I and K all considered that they gained no benefit from using the diary, although all except cases C and K continued to use the diaries throughout the twelve months they were enrolled in the project. This may indicate that there was insufficient education provided regarding the use and purpose of the diary or be due to the fact that their condition was so stable that there was little variation in the symptoms and so minimal benefit to be gained through continued monitoring.

> But there's nothing in there that helps me it's just, it's repetitive as you can see from reading the back lists that I'm just getting so it's the same (Harold).

For the participant in case D the diary acted as a stimulant to increasing her activity. She completed her diary almost every day throughout the project and from the interview it is evident that she gained a greater depth of understanding of her condition through its use.

> You know when I look at it (diary) I want to do more the next day than what I did that day I put it on and so it does push you a bit, to do a bit more (Doreen).

For cases B, J and L using the diary has given them further insights into their illness and the relationships between other factors that may impact upon their daily condition.

> Oh yeah sometimes I can see I'm alright and then sometimes I'm down and like he (partner) in the last couple of months its been because of <partner> because he has a cancer operation for it inside his face and I think that might have upset the applecart (Beryl).

> I found the comments I made, reflecting back over there and refreshing my memory. I thought yes I'm not getting any better why is it coming round again and with this the thing that I've noticed with it, it's getting a pattern to see how long I'm off the antibiotics and when I have to go on back on them. And it has formed a pattern and it's only about three weeks intermingling in between things, I'd forgotten about that. And that was another thing that I was starting to notice and I thought well I must take particular notice of that because off antibiotics for about three weeks and then I'd change and go on to another one. So that's been an advantage (Janice).

It is evident from the interview data that many of the participants thought they gained little from the use of the symptom monitoring diary. However, for those who did express a positive gain from the diary the process appears to have been an important step towards increasing their self-efficacy for self-management. All those who expressed positive experiences were users of the online patient diary. There is further discussion of the diary process in section 6.2.2.3.

HEALTH KNOWLEDGE

The code *HEALTH KNOWLEDGE* relates to the discussion by triad interviewees regarding the extent to which the participants' knowledge about their COPD was altered and also whether this was attributable to their participation within the project. There were differences in the interview data both within and between cases.

The triad interviews in case E demonstrated a lack of consensus within the case in relation to the axial code *HEALTH KNOWLEDGE* as demonstrated in the following quotes. It is evident from this that the mentor considers she has provided additional resources to the participant and that they have had an influence upon his understanding of his illness. However, the participant does not consider this to be so and the research assistant confirms this.

> I've got more out of going to hospital for my health with my breathing than what you people have given me, actually you haven't given me anything to be honest (Edward).

> Yes then he was most upset about oh how he'd never really had any information about COPD (Edward's RA).

> Well the first thing was that he wasn't taking his, one of his medications properly. So I picked that up straight away when I first met him and went to meet him? And although he said it was a daily inhalation or so.....yes and although he said that he couldn't notice the difference I actually showed him a diagram I got some information off the internet, and I showed him the diagrams and how it did activate the, the broncho-dilation region and I wouldn't do, the maximum you know never return to normal but yeah yeah he was quite impressed with that yes and he still insisted that it wasn't working but he did keep taking it. Yes (Edward's Mentor).

In cases A, C, G and I there was agreement within the triad that there was little health knowledge gained through being involved in the project. This is not an indication or judgement of the quality of the mentoring but is possibly a response to where the participants are located within the trajectory of their illness.

> Through this? Umm I'm not convinced about that actually umm maybe it has a bit with our initial questions and investigations and things because she was when I first went to see her she wasn't using her spacer, she'd lent it to the man next door's granddaughter (Constance's Mentor).

Increased perception of the relationship between the external factors, like the weather, and changes in their condition can be achieved from participation in the project. Harold expressed this but did not attribute the knowledge to any factor related to the project.

> And if it's going to rain like it did this morning or there's a change in the air that seems to be when you pick it up or if it's too hot. I noticed that when it gets over 21 and 22 I get as if there's no oxygen in the room (Harold).

Harold demonstrated increased knowledge of his condition through his understanding and regret regarding the impact of past health behaviours on his current health. His mentor considered that he increased his understanding of his disease during his period of participation.

> And I said I would never have smoked if I'd known that was going to happen. We were never told this I mean it was a big in thing when I was younger and that was seventy odd years ago (Harold).

> If I compare the person that I first discussed the use of his medications with in comparison to the person now who understands what each one is and he has a clear understanding of what he should do with his episodes (Harold's Mentor).

In Case J the participant's knowledge of her condition did not increase but the vision of the interactions of her many illnesses was altered. This participant already had an extremely good knowledge of her condition and she used that knowledge to inform others through her interactions with them.

> Her condition and all her other conditions and yeah and what, how she expected even her life you know what was going to happen really you know long term she knew that things were not crash hot and she really wanted to make the most of what life she has and that's the full yeah. So yeah she's a very positive person. Someone you really feel good about when you're there and you feel good to be with yeah and to be involved with (Janice's Mentor).

Janice initiated a discussion about the link between activity and symptom changes and the fact that now carers as well as participant are aware of the impact of changes in activity levels upon her health status.

> I have noticed that in particular because and even my carers do now. They say "what did you do today?" And I say such and such and it was great I said I felt good. They say "well whatever you've got on tomorrow cut it out because you'll sleep all day. Otherwise you'll be ill" (Janice).

It is evident from the triad interviews that participation in the project and the self-management mentoring and self-monitoring did not necessarily result in a change in the knowledge about their health condition. Some triads definitively described that there was an improvement in health knowledge. Others were less sure, with some conflicting assessments, within the triads. This conflict is possibly due to the mentors providing information about their illness to participants but not assessing their comprehension of the information.

PROJECT IMPACT

This axial code provides consideration of changes to participant's lives as a result of their involvement in the project. This code reflects upon changes that are not directly

attributable to specific aspects of the project, but are considered by the triad as being the result of the project participation. Many of these impacts are quite diverse.

In Case D participation in the project has led to changes in the amount of physical exercise the participant undertakes and also the way in which she looks after her health.

> You know once the kids would come up and say you know I'll take you for coffee or something and I couldn't be bothered but now usually I'm just go. I do more walking when I'm downhill (chuckle) (Doreen).

> Well I think I try to look after myself a lot better than I did and you know just the phone calls and you know like you calling in and that it just shows that other people care so it makes a lot of difference I think (Doreen).

Case E demonstrated inconclusive evidence of positive impact from the project. Neither the participant nor the research assistant thought that he had gained from participation but the mentor considered that he had. However, this benefit was very non-specific.

> To be honest with you I don't but...I have improved but through being hospitalised (Edward).

> But he just felt like he didn't...benefit at all (Edward's RA).

> I think that he felt a bit special whether that's good or bad that's not for me to judge but that's the impression that I got yeah and he was you know like...Yes, yes, yes being singled out or whatever for being on the program. Yes. And I think he just enjoyed the participation all round (Edward's Mentor).

One project impact noted from involvement is the increased realistic self-expectations and the understanding of the need to pace activity. This was evident in cases B, D, F, J, K and L.

> Instead of trying to do too much in one day. Like she looked after, her house is very clean and she's one of these ladies who does her regular spring clean which I wouldn't have a clue about. ... But instead of doing it in one week she'd do it over a longer period of time so she's learnt to, I guess learnt to live with the illness rather than letting the illness rule her (Francine's Mentor).

> The Pathways has sort of made me realise that whatever energy that I exert by getting ready and I think it's the breathing for that period of time must be wearing me out to such a degree I've got to sit back and relax and if I didn't have the VPAP machine and sleep so well at night, I probably wouldn't be as fit as I am (Janice).

Through monitoring their symptoms a number of participants have indicated that this has impacted upon them and their ability to recognise fluctuations in their health. This was particularly evident in cases B, D, J and L.

> I am more conscious of the colour and texture of the sputum which is an important thing and he always mentioned that. Had I not have been monitoring that through the day I probably wouldn't really know. Breathlessness yes as well. Because I've discovered a lot of the breathlessness will come if I've got high fluid intake and it's coming from the heart. .... So it's being aware of other things that will create the problem rather than think oh you know oh God my lungs have just about had it because I'm so breathless when it's not, when I say it's not the lungs at all it's exacerbated by the extra fluid (Janice).

However, with the exception of case A all mentors reflected that participants had gained through the increased social contact offered through the project. This impact was in most cases confirmed by the research assistant and acknowledged by the participants in cases B, C, F, I, J, K and L. Thus the social impact of the project appears to have been quite important.

> But then it was I need this help to be able to stay home and it was more like a backup 'cause somebody's going to be ringing me up and I will be alright other than family. So I guess in a way it was reassuring for her. Yeah, having the interest in her in her health, somebody having the interest in her, somebody who was not directly related like a daughter or brother or whoever but was there, another health professional who was interested. That's what's made the difference to her (Francine's Mentor).

In some cases evidence of any positive impact, with the exception of the social impact, is difficult to find.

> I don't know she's gained anything I don't think she ever will, I think that she's just one of those that will go along and she'll do what she's always done and ring a doctor when she feels like she needs to ring the doctor and yeah I don't think anything's changed for her (Constance's RA).

> No, no not really. (pause) No I just go along from day to day (Francine).

The complexity of identifying specific benefits and where to attribute them is evident in the perceptions of the mentor in Case G.

> Oh yeah I'd say there's been some benefit. I think that I'd probably have difficulty of identifying exactly what it was but it's quite multifaceted so I'm sure that something has given her some benefit so (Gaye's Mentor).

Even in terms of Case J the research assistant had difficulty identifying any benefits, this was due to the high level of self-management abilities already evident within this case.

> But still I don't know that her behaviour, like she was so totally on top of all her health issues. I don't know that it was of huge benefit because I don't think anything would have changed for her. She would always been on top of you know when she deteriorates, when she's getting chest infections she'd yeah know (Janice's RA).

Also in contrast to most of the other participants Case J looked at the benefits from a higher level perspective than just her own personal gains and looks to suggest ways to change the project to be of wider benefit.

> I imagine that you would the different aspect of people. The program I'd like to see as saying as a big help is see the pattern forming for when you go on other extra medication (Janice).

It is evident from the triad interview analysis that for the majority of cases some form of positive impact was evident. However, for a number of these cases the impact was through the social contact and "feeling special" rather than direct impacts upon their health. For some the impacts were wider with a greater ability to monitor, interpret and manage the variations in their symptoms. Positive impact from the project was most evident in cases B, D, I, J, K and L.

SELF-MANAGEMENT BEHAVIOUR

This code describes ways in which participants display self-management related behaviours as a result of their involvement in the project. For some it is quite clear that there has been a change in their self-management of their condition and a number of these participants, Cases D, K and L, now have prescriptions for antibiotics on hand to initiate treatment when their symptoms decline. Case J had initiated this prior to her involvement in the project.

> Okay she had the flu there for quite some time and it was really hard to shake it so .... but she had her action plan in place and she already had her scripts ready and you know the Doctor just supplied them and she'd have one on hand and just get it from the Chemist and just rang him once she was getting a tight chest or a bit of a cough or the sputum changed colour and her temperature or anything (Doreen's Mentor).

> Yes, yes, yes, that's all changed. I've got two packets of antibiotics so and antibiotics in there so if I come down with something then you know, then come tomorrow I'll know to start them (Lola).

Cases D, F and I indicated that they have developed treatment plans, in partnership with their clinicians, for when they begin to feel their condition deteriorating. This links well with the self-monitoring within the project.

> Like she recognises her symptoms. She's got a plan of what to do and that includes not waiting too long to get medical help and she's able to identify that different cough the different breathing and signs of infection and things like that to be able to get to her GP, get some antibiotics, take her relievers, rest, that sort of thing. Instead of trying to do too much in one day (Francine's Mentor).

The mentor for Case E considers that his self-management behaviour has changed as a result of the project but there is little evidence to confirm this from the other interviews within this triad.

> Well this program has made him more aware of what's happening. What to look for. He's so tuned into the diary mentality now with a different heading so he, I think he's bright enough to know when something's, when he's starting to go down hill (Edward's Mentor).

Case J appears to have reached the level of self-management where she works in partnership with her healthcare providers to ensure that she has the best outcome possible given her range of illnesses. However, the degree to which this has been influenced by her participation in the project is not obvious.

> Yes I have been out this morning too I managed to get out to the Doctor this morning. So that's just it but I don't let it worry me. I figure that, that's the biggest thing if mentally I think if you let it get to you. See, I'm on Zoloft too, and since I've been on that and I've been on 50 mg for quite some time and I really think that's the one drug that keeps me stable mentally and Hugh had a battle putting me onto it, now he can't get me off it. I said no that just gives me a nice equilibrium and I, by doing this I have the ability not to stress out on major issues with family so therefore I can concentrate more on keeping myself upright and it's working so far but oh if any one has been more than the other with the program mm. I don't think it's any more advantageous to what I've already had quite frankly (Janice).

> Obviously she knows and it's the way that she talks about her other things that's you know I think oh she's right on top of it (Janice's RA).

> [R]ight from day one she just seemed to have it all under control, yeah. .. she had plans for every situation so yeah I really wouldn't say that I've seen any change (Janice's RA).

Janice also points out the potential 'double edged sword' when patients are required to have a great deal of knowledge of and influence over their treatment and the responsibility becomes too much for them.

> [T]he doctors left it up to me too if I go up in fluid, if I'm up to 92 kilos I take five (diuretic tablets). And then each day and when I get back down to 90 I can cut it down to two. Now to me that's juggling a lot with my own medication and medication that I'd rather not be taking and trying to pin them down and say well when can I come off them altogether? And then they say well we've got to get your fluid under control and I say yeah well I know that (Janice).

It is evident from the triad interviews that some degree of self-management behaviour emerged in cases B, D, E, F, I, J, K and L. However, this was stronger in cases B, D, J, K and L, this is evident from the fact that it was discussed by the participant and at least one other member of their care triad.

SELF-MANAGEMENT KNOWLEDGE

The code *SELF-MANAGEMENT KNOWLEDGE* relates to a wider perspective on the concept of self-management and the need for a balanced approach. It demonstrates a wider degree of awareness of the possibilities and difficulties that may arise from the widespread adoption of self-management as the dominant paradigm within health care. This important code was limited to Case J.

> I think for some people it would be now. I think with me I do have a pretty wide knowledge on medication especially the medication that I'm taking, I can control that pretty, or not control it. I know pretty much what I'm taking and why I'm taking it. And I prompt my doctors as to whether I need to still be on it or whether I can come off it or come down. But I would say for a lot of people especially the ones that strut to our meeting they are not ready. They can't even monitor their oxygen and I don't know I say to them why don't you ask your doctor I can't tell you. You must ask your doctor. And they say well shouldn't he, wouldn't he tell me? (Janice).

> I mean years ago it was unheard of that a doctor would say to you now if this, that and something else happens you go straight and get your antibiotics then more or less telling you rather than go and see them and they'd tell you and they'd give you a script. They're basically putting the onus on you which is good to a certain degree and I've always worked in conjunction with the Pharmacist anyway so the advantage of Pathways to me has been that. It's drawn my notice and attention to how many, how often I have antibiotics which means I have to coerce with the Doctor regarding that for repeats so I might cut out the amount of times that I have to go to him (Janice).

Janice's own attitude to self-management reflects a partnership approach in which she talks in terms of people who are 'guiding' her health care rather than attributing responsibility to others. This demonstrates a level of self-management knowledge which is quite advanced.

> I've had a chronic illness for a long time now my immune system must be shot to pieces. So I don't commiserate over that. I, there's nothing I can do

about it or if there is I'm doing it. And I have the utmost faith in the people who are guiding me (Janice).

It is evident from the interviews that reaching a point of self-management knowledge is rare, with only one case displaying this. The other members of the triad in this case emphasised that Janice was a rare case and that they had not experienced this depth of understanding with other participants. Janice has a very broad experience with chronic illness and so the fact that this is the only case to demonstrate self-management knowledge may be due to a combination of multiple factors and not necessarily attributable to the project.

6.2.2.3 Project Experience

This section describes the core category PROJECT EXPERIENCE. This category provides an insight into how the triads describe the case experiences within the project.

There are eight axial codes within the category PROJECT EXPERIENCE. The codes and their relationships are discussed below and graphically represented in Figure 6.3.

- *SYMPTOM MONITORING* relates to discussion about how the cases monitor their symptoms and the impact of this.
- *DIARY FEEDBACK* describes how the triad members talk about the longitudinal diary feedback.
- *DIARY USE* details how the Cases fill in the diary.
- *GOAL SETTING* relates to comments made about the process of goal setting and action planning
- *MENTORING PROCESS* reflects the way the triad members discuss the mentoring process.
- *PROJECT IMPRESSION* describes the way in which the triad members discuss what they think of the project.
- *PROJECT KNOWLEDGE* looks at how the case triads describe their knowledge of the project aims or their understanding of the project.
- *PROJECT REASON* looks at the reason for participation within the project.

Within the category *PROJECT EXPERIENCE* there are two internal feedback loops which then influence and are influenced by *PROJECT KNOWLEDGE*. The first internal feedback loop involves the codes *SYMPTOM MONITORING*, *DIARY USE* and *DIARY FEEDBACK* whereby each code influences the others either in a positive or negative loop.

The second internal feedback loop involves the codes *MENTORING PROCESS* and *GOAL SETTING*. These codes impact upon each other in a close relationship as good *GOAL SETTING* requires the support of the *MENTORING PROCESS* and this in turn influences the *MENTORING PROCESS*.

As noted earlier *PROJECT KNOWLEDGE* influences both of these internal feedback loops as good *PROJECT KNOWLEDGE* can improve the relationships between the codes within these loops. This can be a reciprocal influence.

Both *PROJECT IMPRESSION* and *PROJECT REASON* influence *PROJECT KNOWLEDGE* and are in turn influenced by it as changes in *PROJECT KNOWLEDGE* can result in changes

in *PROJECT IMPRESSION* and *PROJECT REASON*. Thus *PROJECT KNOWLEDGE* is the central code within this category and without it the linkages between the components of the project fall down.

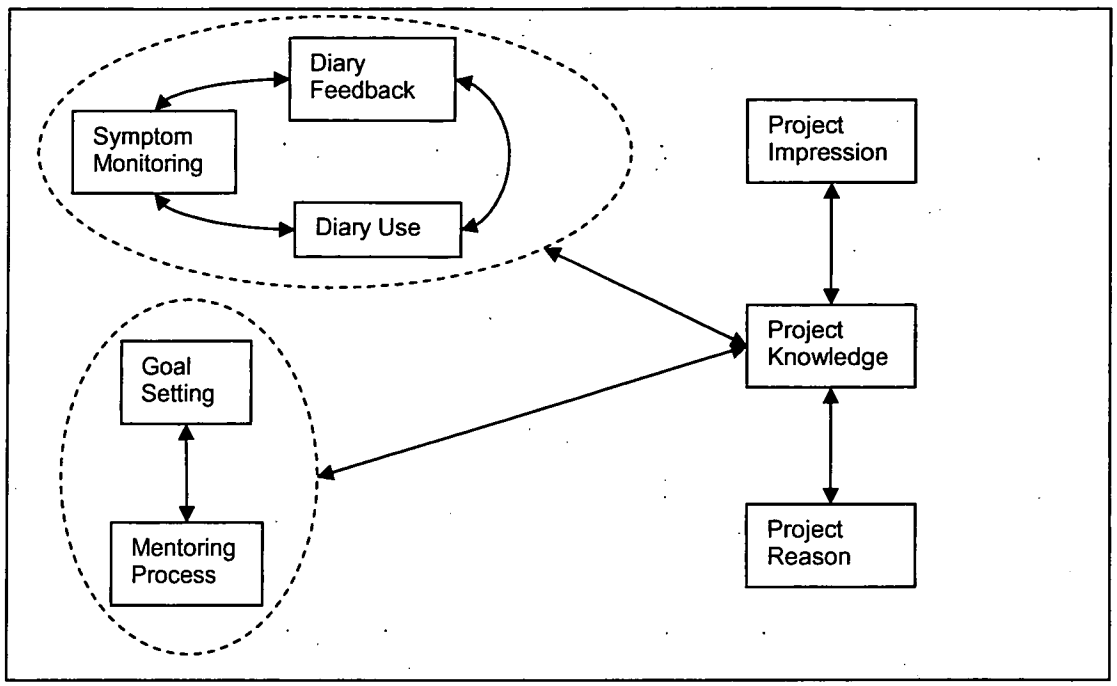

Figure 6.3: Code Relationships within Category Project Experience

Each of the axial codes is discussed below using excerpts from the interview transcripts to further illustrate the codes and their relationships within this category.

DIARY FEEDBACK

The axial code of *DIARY FEEDBACK* describes how the triad members talk about the longitudinal feedback regarding their diary entries received by all participants (see section 2.5.4.3). The response to the diary feedback was quite mixed. Cases A, C, E, F, G, H and I considered that the diary feedback was of little or no use to them. It was evident that these participants did not have a good understanding of the purpose of the longitudinal feedback and so this limited the usefulness of it.

> So when I do it all I put down is how I felt on that day and I mean to say then they .. if I dun it, when I was writing it down then they'd send that back to me. I thought well I don't really want it back (Constance).
>
> No, I don't know how it works (Gaye).
>
> Well there's not point for me is there? It's going to be the same oh well I have looked at it. To me it's the same as what I get and what I give you. Do you read a book twice? No way. Not me (Harold).
>
> Well all I get back is the same as what I've already sent in. It makes sense but why are you repeating what I've already told ya (Ivan)

In contrast cases B, D, J and L all found the longitudinal feedback useful to varying degrees but considered that the patterns formed in combination with their comments were a good way for them to review their condition. These participants anticipated that they would find patterns within the longitudinal diary feedback. For some this did occur, if only temporarily.

> I could see when things were changing by the colours changing (Doreen).
>
> And if I can see it coming on and there's something else to do then I do it (Janice).
>
> It sort of helps you to look after yourself and manage yourself a bit better mm (Lola).

The mentors all found the diary feedback useful particularly as a reference point prior to their phone contacts with the participants. However, it is evident that in many cases the feedback and patterns occurring within it were not discussed with the participants but as a reference for the mentors.

> you could see straight away and that colour coding is brilliant 'cause you can see straight away when what's happening (Edward's Mentor).
>
> When I got on the computer I'd have a look at it before I'd ring her. It just gave me some sort of idea of what colour she was talking about (Francine's Mentor).
>
> Her's was excellent too because she could see when she had her dips and when she had her good days and you could see why and she expressed it really well yeah (Janice's Mentor).

In Case I the mentor has encouraged Ivan to show the longitudinal feedback charts to his GP and discuss his involvement in the project with the GP. As is evident below there are mixed reports on this strategy.

> So the feed back what you give me from the diaries when I've got sufficient amounts say about two months I take 'em to my Doctor. And then she reads 'em and then I say well youse read 'em? And then she says yes I do, so she knows (Ivan).
>
> I encouraged him to take that to show <GP> and show <GP> that he was part of the project and what it involved and all the rest if it so yeah we did talk about that but then when he said basically <GP> thank you very much and well if you don't care well I don't and it was out the door. So that GP interaction there was a little bit of a deficit there (Ivan's Mentor).

The interview data reflects a mixed response within this code. Interestingly those participants who expressed a more positive view within the diary feedback code were those regularly using the online patient diary. This may be because of the immediacy of the feedback or it may relate to their understanding of their illness or the project processes and aims. This will be explored in more detail in section 8.5.1.

DIARY USE

This code details how the Cases fill in the diary - the type of information they put in, whether they continued to fill in their diaries and how they talked about the diary. This code links closely with those of *PROJECT KNOWLEDGE* and *PROJECT REASON* in that the degree of understanding of the project and the reason that participants enrolled in the project appears to impact upon the degree of understanding of the use of the diary.

Many of the participants completed their diaries when they were well but when they started getting sick ceased to do so, this was evident in cases C, E, J and K. This then potentially negatively influenced their ability to interpret the trends in the longitudinal feedback.

> Well when I first started doing them I didn't mind it was just when I was so sick I just couldn't be bothered (Constance).

A number of the participants (A, E, F, G and H) appeared to have the attitude that they were obligated to fill in the diary each day whether they wanted to or not.

> I don't get cheesed off with it. I put it down as a necessary evil. I do find at times that it is a bit inconvenient to have to stop and go and do it. If you know what I mean (Edward).

> Well I don't like doing it but I do do it well put it that way (Francine)

There is evidence of some confusion regarding how to fill in diary but also an impression that there is a right way and a wrong way to do it. This indicates that the participant really does not realise that the diary is there for their benefit and so that they can gain an improved understanding of their person health and changes in it.

> And she's okay with that actually I mean another problem that Francine found was when to fill in her diaries whether to do it in the morning or the afternoon or the day after or when (Francine's Mentor)

> I usually do it of a night-time and anyhow I think to myself and now how did I feel at 10.00o'clock this morning and I think to myself oh I wonder if I was supposed to be writing it for the whole day. This is what worries me more than anything if I am writing it out properly (Francine).

Participants D, J and L in particular noted the benefit of using the diary and recording how they felt each day.

> And when I looked at it I thought well I'm very repetitive. But I'm not you know it's a little bit different, I tried to be as accurate as I could when I'm writing a large screed on things you know and the mood that it takes you but yeah, anyway (Janice).

> Yes, yes 'cause those diaries, if I didn't write it down I wouldn't have given it a second thought about it (Lola).

The completion of the diary each day became quite ritualistic for those participants who found it most useful (B, D, J and L).

> I like to sit and do it at night it sort of finishes the day off (Doreen).

> I've found that not keying into it as frustrating as it is, you know just at this stage the same as everything is, it's part of a ritual I suppose which I know is to my advantage and it all helps (Janice).

Participants A, E, and H all commented that they could write anything in the diary. They appeared to fail to understand the purpose of the diary.

> [A]h as far as that well I could tell you people anything couldn't I? (Albert).

> I worked that part out earlier in the piece. I could make this look real good or I could make it look bad whichever way I wanted it (Edward).

From the interview data it is evident that completion of the diary was viewed as a chore for many of the participants. Despite the religious adherence to completion of the diary displayed by many participants there appears to have been a very poor understanding of their purpose. This appears to be closely related with the axial code project knowledge described below.

GOAL SETTING

The axial code *GOAL SETTING* relates to comments made about the process of setting goals and action planning. Within the interview analysis this was evidently a problematic feature of the project for both the participants and the mentors. Although a number of cases recognised the theoretical potential of the goal setting process they disliked actually undertaking it and rarely felt they completed their goals, usually due to health related factors.

The difficulty of devising realistic goals that are achievable but also will be useful is noted by Participant J.

> Because you're trying and they're not realistic you know. And you sound a bit stupid and a bit funny saying well my goal is to get out the back door today, or within the next week. And I mean you're going to walk out the back door if you can anyway. But there are times when to get out that back door it is an achievement (Janice).

The participant's ability to undertake goal setting and action planning is influenced by their day to day health status. This was noted particularly in cases C, J and L.

> I know the goals and setting goals is great and you know normal procedures of life but I think to myself what goals can you get and can you set when you don't want to be going back, you want to be going forward but you know realistically you can't get there because your health has taken another step down and when you can't physically (Janice).

Differentiating goals and action plans and their benefits from usual behaviour proved to be a challenge. The mentors all expressed the fact that they had experienced difficulties with goal setting with their participants.

> Mmm I think that that's been the main thing for her. but umm yeah because if you do something with her if you set up something I did set up a little action plan with her once and that was just a simple thing - going to the letterbox and back umm everyday and that didn't even happen for a week so she just said 'Oh well I thought about it and I thought well I'm walking to the clothesline and I'm walking here and I'm doing this and I'm doing that and that's the same amount of exercise anyway" so there was no yeah there wasn't any thing (Constance's Mentor).

> <Harold> has not been keen to do set goals or to do action plans so I feel that I haven't really been able to get my teeth into it (Harold's Mentor).

It became evident that some of the participants had a poor understanding of the reasons behind the goal setting.

> Well to me this week I will. Well what do they want me to say? Because I've already said it in the diaries (Ivan).

From the triad interviews it became evident that the goal setting was an extremely poorly understood and accepted process from the perspective of the participants and the mentors. This is possibly due to a number of factors including the understanding of the purpose and process, the ability to set realistic goals and the degree of incapacity of the participants.

MENTORING PROCESS

This code reflects the way the triad members discuss the mentoring process. The role of the mentor is described in section 2.5.5. It appears that the role of the mentor was not understood by most participants.

For many the primary role of the mentor was seen as providing social support and advice. This was confirmed through many of the mentor interviews.

> Oh I still have a good yak to her on the phone and she always will listen to me if I've got problems which is helps a lot especially to do with me health (Constance).

> Oh yes she's nice oh yes I like her. Oh yes well she used to come though. She doesn't come now she rings up and well we still talk and I still act the fool though on the phone like I did (Francine).

> Yes and she's done a lot for me. And I'm sorry to see her go when this course ends (Ivan).

At times the participants challenged the mentor to check how closely they were being monitored and whether the mentor was aware of changes in their condition.

> Well he used to say to me you haven't been looking at the diary have you, or you would have seen what happens (Edward's Mentor).

For the mentors the mentoring process could be quite challenging as they found it difficult to stimulate the participants to extend themselves. They also found the process at times quite repetitive and confining.

> The crux of the matter that you want to talk about he won't talk about, and you sit there very patiently talking about something else hoping to get him back to the point but it's very difficult. The main thing for me has been trying to maintain a rapport that I think we've been able to manage to get together on the phone and not destroy it (Harold's Mentor).

Through the mentoring process at least one of the mentors reported being able to learn from their participants. This process of joint learning is possible when the participant has a good understanding of their health and feels able to discuss these.

> Yes it's not as easy as because I think that she's been mentoring me. I asked for a bit of advice as she's been through so much health wise so yeah. And I mean she's been able to tell me lots of things (Janice's Mentor).

Through most of the interviews it was evident that the primary function of the mentors was one of providing social contact. All participants appreciated this contact but this attitude also proved to make the process of mentoring more difficult. It appears that the true purpose of the mentoring process was quite poorly understood and this is possibly reflected in the code self-management behaviour where the majority of the participants did not experience positive change. This is closely related to the code project knowledge as described below.

PROJECT IMPRESSION

The code *PROJECT IMPRESSION* describes the way in which the triad members discuss what they think of the project. There were evidently mixed impressions of the project and to a degree much of this relates to each person's knowledge of the complexity of the project.

It is evident that some cases (C, E, F, G, H and I) have an expectation that the project will prevent hospitalisations, but without the realisation that this is a partnership model and that their role is not confined to that of passive recipient.

> And then when <RA> comes every three months and just asks me questions and that's it well I can't see where that keeps me out of hospital either (Constance).

> [A]ctually you haven't given me anything to be honest. And nobody has rung me up and said that we think that you are doing so and so it's good for you but when you do such and such it's no good for you. It doesn't come down to that sort of thing. Oh how are you, I could be as fit as a fiddle or I could be dying. You are not going to know any difference, right or wrong (Edward).

> Well I thought it was supposed to keep me out of hospital but I've only been there once so I don't know how that works (Francine).

Others (Cases B, D, J, K and L) were quite enthusiastic about the project and the processes within it and can see that there has been a change in their outlook as a result of the project. This is interesting given their low opinions expressed within the code *GOAL SETTING*.

> No I think its great the way it is. I can't see where you can improve it (Doreen).

> I've found it interesting and good. .... It makes you feel part and parcel of a group who are interested in you and you're not just a statistic. I know that if anything happens to me and I'm put into hospital or anywhere like that there's other people that are interested in the progress because of the program that you've been involved with (Janice).

Case J considers that it is a form of support and looks to the fact that it could be useful to other COPD sufferers as an education aid.

> Exactly so it says a lot for the support groups. So this is basically a support thing you know. The fact that you're writing your findings down makes you write it down and analyse and look at it. So yeah I would say that would make a good support program as well. Looking at it that way. And maybe a few more designed like that so that don't know that and this particular fellow that I'm thinking of it would do him good to sit down and go through a few questionnaires like that on a regular basis. It would probably make him feel good (Janice).

The mentors were generally very supportive of the project and could see benefits for their own practice as well as for the individual participants that they were involved with.

> That's been really good actually it has been really reaffirming and given us things to be thinking about (Constance's Mentor).

> I thought the program overall is really something terrific and it's something to look forward to. Because they say this is what the future is going to be. So we're actually in on the ground floor being part of the, well the forerunner the big stage trying to look at it (Doreen's Mentor).

> As I say it was a challenge and something different in more of a direction I guess in the way we are heading (Francine's Mentor).

> I think that it's the thing that for me personally yeah it's been good it's been, I've learnt heaps personally, professionally and academically and more

> importantly I think it's the transferring of the project to the participants to get the best outcomes of where you want to be (Ivan's Mentor).

The research assistant and particularly Ivan's mentor commented upon some limitations they had observed within the project.

> [T]he language hasn't been simple, the people that we are dealing with are simple people who need simple explanations and our terminology has been borderline between academic and professional. Yet the people that we are dealing with are down to earth every day people (Ivan's Mentor).

> I think that the type of participants that have been part of the project haven't contributed to being a very successful outcome to that (Ivan's Mentor).

From the triad interview data it is evident that there were mixed impressions of the project. Although most interviewees displayed an overall approval of the project there were mixed expectations some of which were at odds with the overall aims of the project. The mentors and many of the participants were supportive of the project but it was evident that many failed to piece together the overall relationships within the project. Once again this code links closely with the code *PROJECT KNOWLEDGE.*

PROJECT KNOWLEDGE

This code looks at how the case triads describe their knowledge of the project aims or their understanding of the project. The project was quite a complex one and it is evident that may of the interviewees failed to fully appreciate the interrelationships between the different parts. The majority of the participants had a very simplistic view of the project or compartmentalised the various components.

> Well it was something you wanted to know how people were going to feel over a certain time of being sick you know and you know good days and bad days or if you get worse or you're going to get better or something that's the way I look at it. I mean I don't know if that's the way it is supposed to be (Francine).

> No. I didn't. But I knew it must have been for some reason for what I had, the emphysema isn't it? No not really no. Only if I felt any different you know or any worse (Gaye).

> I just thought that I'd fill in that form and try and help other people if they could put it together and do their analysing (Harold).

> But at the same time he took everything as individual bits and he did each little bit you know and he seemed to be quite happy and he seemed to gain. Yes his diaries from what he said he was filling them in and noting what his symptoms were like etc. so yeah he just compartmentalised it all (Ivan's RA).

The complexity of the project and the language used during the recruitment process has had an impact upon participant's project knowledge. This was expressed in detail by Edward.

> That day that I spoke to <recruitment officer>, remember <recruitment officer >, and she was very hard to understand and to have to sit and talk to a doctor that's hard to understand at the best of times, she cannot give you the wording that you want to hear. If it had been from the likes of yourself, like an ordinary layman type explaining something to you, you would get it a lot clearer I'm sure of that (Edward).

> The other thing that I have found with her speaking to me is be it a professional person I had a lot of trouble understanding the words. They only know certain words and certain things in here. They don't know how the ordinary layman talks and puts that through (Edward).
>
> But that's what I find that professionals are very, and not all of them, but some of the people that with a sort of different accent. They can't express themselves the way that we have been taught to be expressed to us.....and that's one fault that I did find with it, that she couldn't tell me exactly what was going on and she was in a hurry anyway and I had to wait for her to come and I was being discharged and I was ready to go home (Edward).

The mentors and the research assistant had varied views of the participants' knowledge and understanding of the project. Those that were identified as having a good knowledge and understanding were cases B, D, J, K and L.

> I thought her understanding of the program was fairly good and she also had a really good action plan already with her doctor (Doreen's Mentor).
>
> Possibly not, I don't know that she's sort of, she'd seen the diaries I imagine but I don't, I think because she's fairly well too she probably didn't really think about it too much. She was mainly doing it because for research and it was going to help people but I don't think for herself that she was really thinking about it (Francine's RA).
>
> When I initially talked to her I didn't think her understanding was particularly good about it. She sort of understood bits that, some of the componentry of it but I think that perhaps when it was presented in the hospital that it was all a bit overwhelming and stuff (Gaye's Mentor).
>
> [Y]eah her understanding yeah it was excellent (Janice's Mentor).

Understandably given their training by the project, the mentors expressed a greater knowledge and understanding of the project. However, on the whole this knowledge appeared not to be conveyed to the participants.

> I always believed the people that were going to participate were going to be assisted in being or taking on ownership of their own health problems and we were going to facilitate that (Ivan's Mentor).

From the interviews it appears evident that there was a mixed degree of project knowledge. Those participants identified as having a good understanding were all, with the exception of case K, cases who adopted the online patient diary. This may indicate that one of factors in the decision to use the online patient diary is a high degree of knowledge and understanding of the project. The other major factor identified from the interviews is the importance of the language used at the recruitment of the participants. These factors will be examined further in section 8.6.2.

PROJECT REASON

This code looks at the reason for participation within the project. This code is important in that the reason behind a person choosing to participate in a controlled trial has the potential to impact upon the manner in which they actively participate and so impact on the overall results.

Most of the case participants expressed that they were participating because they were asked to or because they thought that it would help other people. This attitude of

altruism is not in keeping with the overall aims of the project to increase participants' self-efficacy for self-management.

> I was asked to do it and so I did it (Edward).
>
> I just do it because I told <recruitment officer> that I would and that was it. ... But, I mean I don't know if this part is going to make me any better or not you know. But as I said if it is going to help somebody and I mean I don't know if my little bit will help but we'll just see (Francine).
>
> I thought well if it helps somebody else everybody's got to be different. I would be interested to see what different effects everybody has. They might come up with something (Harold).
>
> I just thought that I'd have to do it (Gaye).
>
> I felt really I was giving something back you know because I didn't know anything about it (Kerry).

The mentors expressed similar interpretations of the participants' reasons for participating in the project.

> I think Constance is someone who will do what she thinks we want her to do because that's who she is rather than that's what she wants to do or she sees the value in it or she understands it (Constance's Mentor).
>
> I think that's a lot of what is involved. They are sort of, really wanting to do the right thing by us and I really detect that in her because she really wants to help and to do the right thing but she doesn't want to get involved on another level or she doesn't feel she can (Constance's Mentor).
>
> I think that he believed that being part of the group .... he believes that any contribution that he can make is a worthwhile contribution because one it helps him and two it may help someone else (Ivan's Mentor).

Cases D and L were the only participants who expressed the impression that they would benefit from being involved in the project.

> Well I thought that if I could get something out of it as well that would be good (Doreen).
>
> Yeah, helping me but if you get benefit out of it then good luck to you (Lola).

From the interviews it is evident that the majority of participants enrolled in the project for altruistic reasons. Only cases D and L anticipated any personal benefit. This is important as it relates closely with the project knowledge and has the potential to result in people being recruited into projects who have different expectations and in this context this may have negatively impacted upon the participants' ability to achieve an improvement in their self-efficacy for self-management. This will be further explored in section 8.6.2.

SYMPTOM MONITORING

The code *SYMPTOM MONITORING* relates to discussion about how the participants monitor their symptoms and the impact of this. This code is closely related to those of diary use and diary feedback in that the attitude to one can impact upon the attitude to the others.

There was some criticism of and confusion about the measures used and the fact that people's condition changes during the course of the day. This confusion may be due to poor project knowledge.

> Not really because the symptoms weren't really good enough for my health part of it. All they wanted to know was how I was breathing. Did I feel alright? Well I felt real good this morning but by lunch time I was down in the dumps and gone. I got two different things in one day. What am I supposed to put down? Can't pick them both because it won't work and I couldn't write them in (Edward).

> Yes and I think to myself now say a teaspoon and sometimes I cough up more than a teaspoon at one cough. Then I don't cough during the day it is only in the morning and at night-time. See. During the day I'm alright (Francine).

Participants from cases A, C, E, F, G, H, I and K reported little benefit from the symptom monitoring. It appeared that many of these participants did not understand the reason for the monitoring nor how to interpret the changes.

> It just goes straight over my head or that sort of thing. The less I have to think about the better I am I think (Francine).

> Well I know what's happening. I'm tightening up. I don't need to look at it. It's in me that's happening. Well that's my attitude (Harold).

In contrast Cases B, D, J and L found that the symptom monitoring was useful and that it tended to become instinctive after a period of time.

> You sort of know now by putting it in day by day you sort of keep track of whether you are getting any better or any worse sort of thing (Mrs D).

> I wake up in the morning and I think oh God you know I feel as though a truck has run over me and I get up and go to the toilet and sometimes I can get in there and back and I think oh gee I did that without my oxygen and then other mornings I'm puffing to such a degree that I think oh no not another day like this. And you start off saying oh it has. Then I start coughing and I think well have I got any junk down there and quite often I do have and then I think right I'll go and use the puffer that <physiotherapist> gave me and this one here and I know that I do five minutes or so with that and that'll move it and that's what I have to do the rest of the day. Then I monitor the sputum and then I monitor the colour. So yes, that has given me a regular in-look sort of thing to test myself into doing it. And then at the end of the day if that doesn't work I know I'm in for another bit of a battle.....so I get an antibiotic so yes, overall with the particular schedule it has made me aware and I can follow up on it (Janice).

The mentors expressed a higher opinion of the role of the symptom monitoring than the participants.

> I guess he reflects a little bit more on his shortness of breath and the sputum, the colour of the sputum, the amount of the sputum, so I guess he has a better understanding of the symptoms and when to actually access his GP in comparison to when he would have when he first came onto the program. (Harold's Mentor).

Symptom monitoring is a key component of the process yet it is evident from the triad interviews that there was a high degree of misunderstanding about this. This may be due to the participants' level of project knowledge or alternatively to the participants

experiencing prolonged periods of stable heath and so minimal change in their symptoms. Those participants who found the symptom monitoring useful were ones who also chose to use the online patient diary.

6.2.2.4 Technology Experience

This section describes the core category TECHNOLOGY EXPERIENCE. This category explores the experiences of the triad in relation to technology in general and more specifically the online patient diary introduced through the project to those participants who requested it.

The category TECHNOLOGY EXPERIENCE has seven underlying and inter-related axial codes. The codes and their relationships are discussed below and graphically represented in Figure 6.4.

- *COMPUTER ATTITUDE* describes how the triads discuss technology and in particular computers.
- *COMPUTER EXPERIENCE* records any past experience or lack of experience with computers or other technologies that members of the care triads describe.
- *COMPUTER INITIATION* describes how the cases got started with using the online patient diary and the computer.
- *COMPUTER REJECTION* describes how or why participants made the decision not to use or to cease using the online patient diary..
- *COMPUTER ISSUE* describes any issues identified during the interviews relating to using the online patient diary or computer.
- *COMPUTER USE* describes the range of things the participants used the computer for.
- *COMPUTER IMPACT* reflects how using computer has impacted on the project experience or life of participants

COMPUTER ATTITUDE influences and is influenced by *COMPUTER EXPERIENCE* and these two codes in turn influence and are influenced by *COMPUTER REJECTION* or *COMPUTER INITIATION* and form an internal feedback loop. *COMPUTER USE* is initially influenced by *COMPUTER INITIATION*. *COMPUTER USE* is also influenced by and influences *COMPUTER ISSUE* which in turn can influence *COMPUTER REJECTION*.

COMPUTER IMPACT is the final code and this is both influenced by and influences *COMPUTER USE* and *COMPUTER IMPACT*.

Each of the axial codes is discussed below using excerpts from the interview transcripts to further illustrate the codes and their relationships within this category.

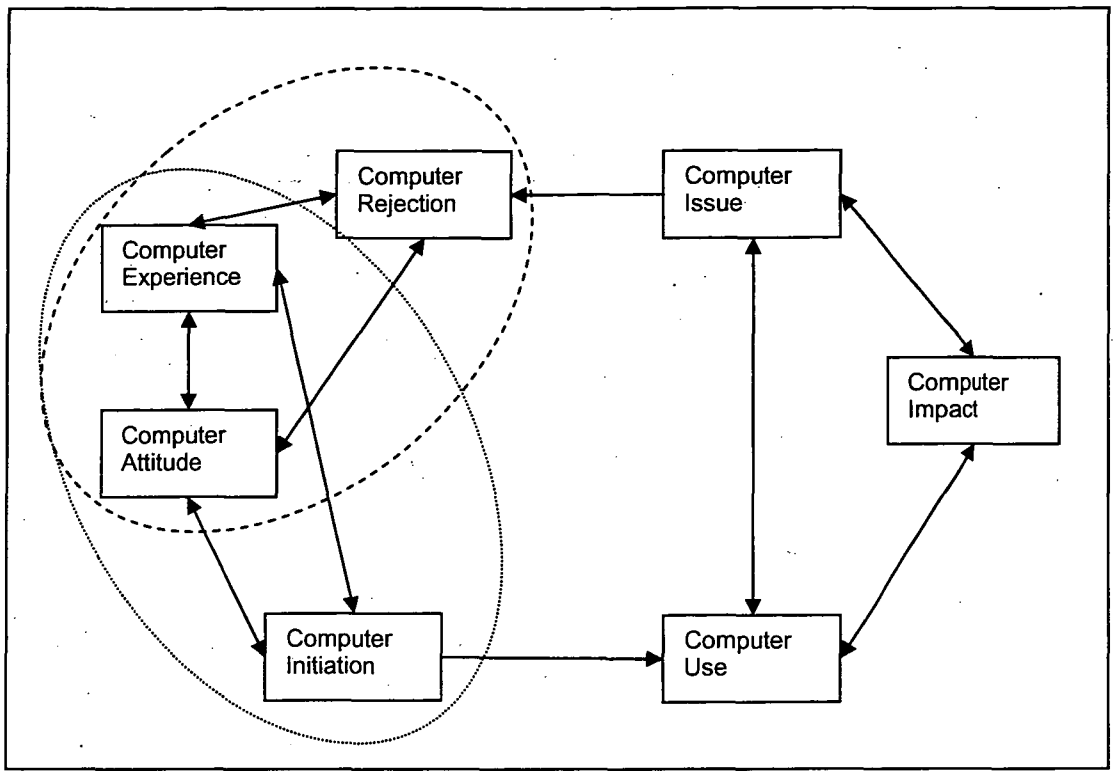

Figure 6.4: Code Relationships within Category Technology Experience

COMPUTER ATTITUDE

The code *COMPUTER ATTITUDE* describes how the triads discuss technology and in particular computers. This code includes the views of the mentors as well as the participants as there is the potential for one to impact upon the other.

The attitude towards the computer has the potential to impact upon whether or not the participant chose to use the online patient diary. Constance had a positive attitude towards the computer from the start although she primarily used it to play games rather than project related tasks.

> To keep me occupied I think (chuckle) stop me from being bored (Constance).
>
> I'm just that the computer's a good companion to me at times (Constance).
>
> I mean well she loved the computer for games (Constance's RA).

Interestingly Doreen had previously tried to learn to use a computer but could not. Through her participation in the project and her subsequent use of the computer she has altered her attitude towards the computer.

> [I]t was quite easy once I'd made up my mind to learn how to do it. So (pause) well I went to university for three years and I just couldn't learn I probably didn't want to I don't know (Laugh) (Doreen).
>
> When I came back on deck (after sick leave) she had the computer and I was talking to her last time I believe or the one before and she is really enjoying the computer (Doreen's Mentor).

Edward was a little sceptical about the computer in the first instance but has gained confidence and is considering extending his use to other purposes.

> I wasn't real keen on the computer bit to start with as I told you, I didn't think that anything would come of it (Edward).
>
> Now that I can I'll learn how to do it (use Internet) yes and it will be interesting as to whether I can get off it and I will even put a few dollars and buy a printer for it in case there is something that comes up. I'll never buy anything off it, because I don't believe in that sort of stuff on it for other people to know. But if there is a recipe I'll take it, take it off and <wife> will do it, use it and if it is any good we'll keep it. ... I will put in a, I'll get a printer put with it (Edward).
>
> Oh he just, he really enjoyed it. He enjoyed learning it. He enjoyed the challenge and I think that it was really good for him because it took his mind off his health problems and gave him something new to look forward to doing, yeah. No he really enjoyed it (Edward's Mentor).

Francine expressed the feeling that she was not clever enough to use a computer even though she had a great deal of support from her daughter.

> I mean my sister's real brainy, her and her husband and neither of them can. <Daughter> offered to send me to school and all and I thought I'll be the oldest and the dumbest one there (Francine).

In Case H the participant was very positive about the computer and wanted to start using the online patient diary but he had no landline and refused to have one installed so could not have the computer installed. All members of the care triad in this case considered that the computer would have had a positive impact upon his participation within the project.

> So I thought I would have done better with a computer but now I'm not interested and I can't be bothered with it (Harold).
>
> Yes so whether or not he would have been more interested and he would have been good with the computer he would have actually been one, who would have been. Yeah I reckon he would have managed that really well and it might have changed his whole slant on the thing as well (Harold's RA).
>
> Yes, he was very happy about the idea he was quite excited about the idea of a computer and then quite deflated when he told me that wasn't going to be the case (Harold's Mentor).

The mentors expressed mixed attitudes towards the computers but all thought that their skills had improved through the course of the project and none reported continued avoidance of computers at the interviews. They did however express some frustration with computer use within the project[5].

> I don't think I intentionally do but I'm usually busy enough to do what I'm doing that it wouldn't be a priority to get onto it. Yes. So I suppose you could say that's avoidance without avoiding it (Janice's Mentor).
>
> I'm not computer literate and then I stuff up and then I say I need your help (laughter) and it does take time and I mean that I'm not that comfortable with the computer and it is it's quite challenging but it's been good too to be able to go in there, turn it on, get on the site and things (Francine's Mentor).

[5] This is explored in greater detail in a forthcoming paper.

> But I am keen to get involved in it and I realise that I can't get away without it any more (Constance's Mentor).

More than half the participants interviewed expressed a positive computer attitude. This attitude was required to initiate the use of the online patient diary and so those who expressed negative attitudes did not opt to use the online patient diary. The mentors expressed a wide range of attitudes towards computer use but all reported that their attitude had improved though participation in the project.

COMPUTER EXPERIENCE

The code *COMPUTER EXPERIENCE* describes any past experience or lack of experience with computers or other technologies that members of the care triads describe. Cases A, B, E, F, G, I and L had no experience with computers and expressed difficulty using other technologies, for example mobile phones.

> I'd never touched a computer in my life, never (Edward).

> I've never used a computer, I left school when I was about fourteen and there wasn't much about in them days, like computers (Gaye).

> No I don't think I'd be capable of using it I mean God I used to muck <Daughter>'s mobile phone up I don't know why she ever bought me one anyhow now she said now she was going to buy a new one and I said have this one that I've just got. I can't use the old one so what do I need a new one for (Francine).

> I 'aven't got a computer and I don't even know how to work that (pointing to mobile phone packaged in box) (Ivan)

Constance had experience playing games on a computer at her daughter's place and was quite comfortable with this. Harold expressed similar experiences.

> Oh I could play the games yeah but anything else I was wouldn't have had a clue how to do (Constance).

Doreen had previous experience of trying to use a computer but these experiences were quite negative.

> None. I just couldn't learn. That little arrow (cursor) wouldn't go where I wanted it to (Chuckle) so my kids just gave up on me. I gave up on me too actually (Doreen).

Janice was the only participant with much prior computer experience. She was also the only participant who owned her own computer. However, she considered that her experience was lacking.

> Well it's interesting. It's like as though I've never used the blasted computer so I've discovered. With all the software that's coming through. And they say that its user-friendly well I'm looking for the element of difficulty in everything. What happened here I did do an introductory course twenty years ago and used computers quite adequately but like spoon feeding where you to have your package and you'd work on it (Janice).

> So in answer to all that my knowledge is not, I'm thinking, not enough to know how to get out of different problems with the new software and that's only because I'm not, I'm not stupid, it's just that I've got frustration with concentration at the moment (Janice).

In all cases except case J the mentors had more experience with computers than the participants. However, this experience was, in most cases, not extensive nor was it positive. The mentors in cases C, E, F, H, J and K reported that they used computers as little as possible and that they generally had a history of having bad experiences when using computers[6].

> You know so I've just played around a little bit and found my way around a few things but no my computer skills are very sadly lacking I'm afraid (Constance's Mentor).

> Oh very limited, very limited. I liked them but I'm frightened of them. I'm not as bad as I was. I'm just frightened that I'll make a mistake and wipe off information that I shouldn't (Francine's Mentor).

The triad interviews identified a wide range of computer experience within the group. A number of participants had poor experiences with technology and did not have the interest nor the confidence to elect to use the online patient diary. It appears that there may be a relationship between computer experience and the uptake of the online patient diary within this project.

COMPUTER IMPACT

The code *COMPUTER IMPACT* reflects how using computer has impacted on the project experience or life of participants. This code is confined to those cases where the participant chose to use the online patient diary.

The introduction of the computer in Case B proved to be quite a negative experience. Beryl did not spend much time trying to learn or use the computer. Beryl's experience is discussed in more detail in section 7.3.5.5.

> [S]he hated it and she just found it too difficult to deal with and I think her husband didn't like it either. And that might have been the main reason I don't know. I think that probably if she'd been left to her own devices that she would have embraced it because she does take on everything else (Beryl's RA).

> It was just I should have persevered a bit more with it but when you get a seven year old on there and says you do it this way Nan and you do it that way Nan and I ..NO (Beryl).

In Case C in spite of her initial intentions to use the project online patient diary Constance rarely used it. However, there were other impacts noted from the introduction of the computer, with the computer indirectly altering her health behaviour in that when she was playing games on the computer she did not smoke, and it also prevented boredom.

> Well when you asked me did I want the computer to do the pathways that's what I thought I was going to do all the time (Constance).

> She did tell me once that she had this little game she used to play and that used to stop her from wanting to smoke cigarettes. She'd be there for hours and she'd play it and she's realise that a long time had gone past (Constance's Mentor).

> So no that sort of saved me from just sitting there (Constance).

---

[6] The mentor technology experience is the subject of a paper currently being developed.

Despite appearing to quite enjoy the computer Edward considered that there was no gain from it in relation to his health. This is in keeping with the overall negative impressions Edward expressed in relation to the project.

> From what I can see that there's nothing on that computer that can improve me, and you people are not telling me anything that can. Whether you are getting anything out of it or not, I don't know but if you are, why don't you tell us? (Edward).

In Case D the online patient diary was deemed to be preferable to using paper diaries but Doreen also reported other benefits such as relieving boredom.

> Oh I think it is a lot different. because you can sort of sit there and you realise by looking at the computer you know the way you are where with the paper you had to turn pages, you know, and you sort of didn't realise, you know, one day from the next. Where on the computer you can see the whole lot (Doreen).

> Well it has because I've, you know, I've got that to do now. Instead of just nothing (chuckle) sitting around being bored. I find I quite like getting on the computer (Doreen).

At times, particularly when she was unwell, Janice found it frustrating using the computer as it was a slow dial-up connection. However, she also used the computer to relax by playing games before bed.

> It's just that when I get a little bit down everything's an effort and when it comes to the evening with the time trying to put the program through and my computer being as slow as it is, I get frustrated. But then as soon as I've got it on, I get it to you and then I play a game of solitaire or something and I relax and then I'd go to bed (Janice).

Of the cases that chose to use a computer case B experienced a negative impact, case E reported a neutral impact and cases C, D, J and L all experienced positive impacts. The impacts reported were not limited to direct project related impacts. All these cases reported psychosocial benefits in terms of the computer being company or a distraction. These impacts can be important and will be explored further in section 8.6.1.

COMPUTER INITIATION

The code *COMPUTER INITIATION* describes how the cases were approached about and why they did or did not use the online patient diary and the computer.

In cases B, C, D E and L the participants thought that since they had plenty of time they would learn to use a computer. They did not express any indication that they thought it may have the potential to change their health behaviours prior to the introduction.

> Well I thought it would be good you know to learn how to do it and the kids you know, know how to use computers so I get a bit of help off them but I just thought it'd be good you know to learn how to do it and its something different (Doreen).

> I was asked to. And seeing as I had plenty of time up my sleeve I thought that I would have a go. It is as simple as that. Perhaps if I had been eighty percent fit I wouldn't have done it because I would have wanted to go outside but seeing as I wasn't and according to what the doctor was telling me I might

> never ever get to that stage again there might be some that do. I learnt how to use the computer, not that I'll probably ever want one but I've done that and probably some help for someone else. That's all it was. As I said probably if I had been healthier I would have been outside working (Edward).

In Case H the participant indicated a desire to have a computer installed and use the online patient diary but he did not have a landline and did not want to pay for one so was unable to have a computer.

> Well I was going to have a computer I thought I could be buggered about with it here and I've got the power plug there and I just refused to pay their line in fee <phone line costs>. The phone bloke was up in there but I think that this enough. I don't think that I'm bothered at with the computer anymore (Harold).

Cases G and I did not remember being asked if they wanted to use a computer at all. This may be due to distance between the offer being made and the interview or it may be that they were not approached.

> I can't remember or if I did I would have said no because I don't understand computers. And that's being honest I mean it's 'ard for me to get round this telephone 'cause I'm used to Morse key (Ivan).

The mentors tended to be quite harsh judges of whether their participants would use a computer despite being able to see the potential benefits. This did not necessarily reflect upon the outcome with case E choosing to use the online patient diary despite his mentor anticipating that he would .not

> No I wouldn't. Not at all. Because of his age, his background, his socio-economic roots etc, etc. No, no way (Edward's Mentor).

Janice was the only participant within this group who had her own computer. At recruitment Janice responded positively to the computer and commenced using it as soon as she possibly could after the project six week initial non-IT phase (see section 2.5.4). Janice's computer initiation was requested at the time of recruitment.

It is evident that the participants were approached about using the computer at different times. It was planned within the project protocol that the initiation would be standardised but it appears this was not the case. The mentors and research assistant were responsible for initiating the computer use and it appears that to some extent they acted as gatekeepers using their own judgement of the capacities of the participants to withhold the approach. This is discussed in greater detail in section 8.5.1.

COMPUTER ISSUE

The code *COMPUTER ISSUE* describes any issues identified during the interviews relating to using the online patient diary or computer. This code is confined to those who chose to use the online patient diary. Cases B and C found the process of connecting to the Internet using a dial-up connection confusing. They each had unsuccessful attempts although there was no technical reason for this.

> But then I'd get confused trying to get into the internet (chuckle) and sometimes it comes up and I've made a mistake somewhere and I can't work out where I've gone wrong. So my daughter always reckons that you can't really break it but I'm worried about doing that (Constance).

Cases D, J and L reported some technical issues with their computers but these were minor and easily sorted out either with family support or through the project.

> Yeah it did freeze on me there for a few days I think I done something wrong though. So I had to wait for <son> to come and fix it. So I said to him "what's wrong with it?' and he said "don't worry about it Mum its not the computer its you!" (laugh) (Doreen).

> Yes, I was fiddling and I put white onto white (Lola).

For Case J a major issue has been with her eyesight causing difficulty viewing the screen. Janice had cataracts removed during her time on the project.

> What I needed to do was to print it out. Because I'm pretty useless when it comes to visually looking at anything back on the screen. Print it out and then you can see whether there's a deviation here there or anywhere else (Janice).

> Her main problem has been her eyesight hasn't it because that's difficult to see. Sometimes she presses the wrong key. Yeah, so yeah she was really eager to do that (Janice's Mentor).

The use of dialup Internet connections proved to be an additional complexity in a number of cases and this should possibly be avoided in future projects of this type. However, there were minimal issues with the computers or the online patient diary reported through the interviews. Those that did occur were due to factors external to the project such as the participants altering settings or the impact of health issues.

COMPUTER REJECTION

The code *COMPUTER REJECTION* describes how or why participants made the decision not to use or in case B to cease using the online patient diary.

Most participants who opted not to use the online patient diary, cases A, F, G and K, suggested that they were too old and or not technically minded enough to learn to use a computer.

> Oh yes and I'm not going in for any of that and my daughter offered to give me hers why because she bought a new one and I said no way I can't even use a mobile phone. I've got it here for two years and I still don't use it. No I'm not in for any of that I'm sorry. No I don't think I'd be capable of using it (Francine).

On the whole the mentors and research assistant in the triads where the participants chose not to adopt the online patient diary were quite negative about the abilities of the participants in relation to technology.

> I asked her in the beginning whether she was going to be a person who would be interested in having a computer and she just said no. It was going to put that much more stress on her to learn a new skill and that she's not mechanical minded or technical minded, something like that which you could see she would not be, she was anxious enough without having to learn something like that and that was reasonable (Francine's Mentor).

> I, just my assessment of <Gaye> would be that it would be something that would be beyond her comprehension, getting used to using a computer, with yeah (Gaye's Mentor).

> Yeah yeah yeah. I mean I can't actually imagine her as having the technical ability to do it anyway but I could be totally wrong there because she did surprise me (Gaye's RA).

Case B was the only case where the online patient diary was initially adopted and then rejected. This was due to a number of psychosocial factors. Case B is discussed in more detail in section 7.3.

The interviews reveal a number of reasons why participants rejected the online patient diary. For some this was because of their perceptions about computer users that did not fit with their self-image for example they were too old or not clever enough. Whether the mentors' attitudes had any impact upon this or not is questionable but many of the mentors could not imagine the participants using computers, despite being able to see the benefits. Case B was the only case that rejected using the online patient diary after it was introduced. This was for a range of complex social reasons but she also expressed that she could have done it if she had persisted.

COMPUTER USE

The code *COMPUTER USE* describes the range of things the participants used the computer for. Cases C, D, J and L all reported using their computers to play games.

> <Daughter> loaded a game on it. It sort of takes my mind off things otherwise I sit here and start stressing out about being bored but if I get on there concentrate on these games well (Constance).

> I've got a game on there you know I like playing that cause you've got to beat the score every time and that I quite like that one. And it doesn't cost me anything to gamble on that (laugh) (Doreen).

Cases D and J use their computers for email and/or instant messaging.

> Yeah actually <granddaughter> ... she's got an email thing (MSN) on there and when I'm getting into mine hers pops up so I talk to her friends (Daphne).

The mentors display some knowledge of what the participants are using their computers for.

> She's playing games on it and she gets up to a certain level then the relative whoever or friend comes in and then if they beat her score she's got to beat theirs. So it's become a bit of an extra interest for her too (Doreen's Mentor).

> She tells me all these things that she does and I think oh my God she knows so much. I've feel a bit less capable about the computer than what she is probably but yeah (Janice's Mentor).

Cases D, E, J and L all report either using or intending to use the computer to look up information on the Internet.

> Oh I think we looked up umm oh my granddaughter had something .... and we went into it (Internet) and looked up what was on her certificate (Doreen).

> You get a lot of diabetic recipes come through the TV and if you want that recipe they'll tell you to click on it and all that sort of business which I will be able to do and look and take off what I want so once I have mastered it a bit better (Edward).

Case J is the most sophisticated computer user in the group and she uses multiple software applications. She also finds that it is an enjoyable way of passing the time.

> Then I have a game of solitaire ... to scan photographs and stuff .... it was one of these PowerPoint things .... I haven't answered my emails or anything else; people think I'm off the planet (Janice).

> And I'm about to use it for a lot more you know with my printing and that which I'm starting to enjoy but I need to get <daughter> down and she sets me up with it. I've run out of printers ink now so (Janice).
>
> there's so much technology around I could stay put in here forever and a day and I'm enjoying it at the moment because it's like a cocoon and I don't have to be polite and strain myself (Janice).

From the interviews it is evident that the participants use their computers for a wide range of purposes. All participants use or intend to use the computer for purposes other than the project online patient diary. For all participants except Janice this use of computers and extension of it into other activities is new.

The next section (6.3) will discuss in greater detail the relationship between the core categories OUTCOME, PERSONAL EXPERIENCE, PROJECT EXPERIENCE and TECHNOLOGY EXPERIENCE, as identified through the triad interview analysis.

6.3 Relationships between Core Categories

This section explains the relationships between the core categories identified through the triad interview coding process and explored in detail in section 6.2.2. Essentially it is evident from the triad interview analysis that OUTCOME is the result of PERSONAL EXPERIENCE, PROJECT EXPERIENCE and TECHNOLOGY EXPERIENCE and that the influence of PROJECT EXPERIENCE and TECHNOLOGY EXPERIENCE is mediated through PERSONAL EXPERIENCE (see Figure 6.5).

Each of the four categories is defined below:

- The category PROJECT EXPERIENCE provides an insight into how the triads describe the case experiences within the project.
- The category TECHNOLOGY EXPERIENCE explores the experiences of the triad in relation to technology in general and more specifically the online patient diary introduced through the project to those participants who requested it.
- The category PERSONAL EXPERIENCE encompasses the way the different interviewees within the triads describe or reflect upon the many facets of personal experience in relation to each case.
- The category OUTCOME relates to outcomes, changes in behaviour or attitudes that participants, mentors or the research assistant consider are attributable to participation in the Pathways Home Project. This category is closely associated with the project aims.

From the triad interview data it is evident that the central category is PERSONAL EXPERIENCE. The category PERSONAL EXPERIENCE is the conduit through which both PROJECT EXPERIENCE and TECHNOLOGY EXPERIENCE influence the category OUTCOME.

PROJECT EXPERIENCE is influenced by PERSONAL EXPERIENCE. This relationship reflects the fact that PERSONAL EXPERIENCE can have an impact upon how the individual interacts with the project particularly in terms of the codes project knowledge and project reason. PROJECT EXPERIENCE in turn influences

PERSONAL EXPERIENCE through the impact of the axial code *PROJECT KNOWLEDGE* upon those of *HEALTH UNDERSTANDING* and *HEALTH BEHAVIOUR*.

TECHNOLOGY EXPERIENCE is influenced by PERSONAL EXPERIENCE this occurs particularly through *HEALTH BEHAVIOUR* and *HEALTH GENERAL*. However, the stronger relationship is the influence of TECHNOLOGY EXPERIENCE upon PERSONAL EXPERIENCE through *COMPUTER IMPACT*.

There is evidence that TECHNOLOGY EXPERIENCE may be influenced by PROJECT EXPERIENCE through *PROJECT REASON* and *PROJECT KNOWLEDGE*. There is a stronger influence from Technology Experience on Project Experience through *COMPUTER USE*, *COMPUTER ISSUE* and *COMPUTER IMPACT*.

The influence of PERSONAL EXPERIENCE on OUTCOME is strong through the influence of *HEALTH UNDERSTANDING* and *HEALTH BEHAVIOUR* upon *HEALTH KNOWLEDGE* and *SELF-MANAGEMENT BEHAVIOUR*. There is the probability of these resulting in a feedback loop but this is not clearly evident from the triad interview data.

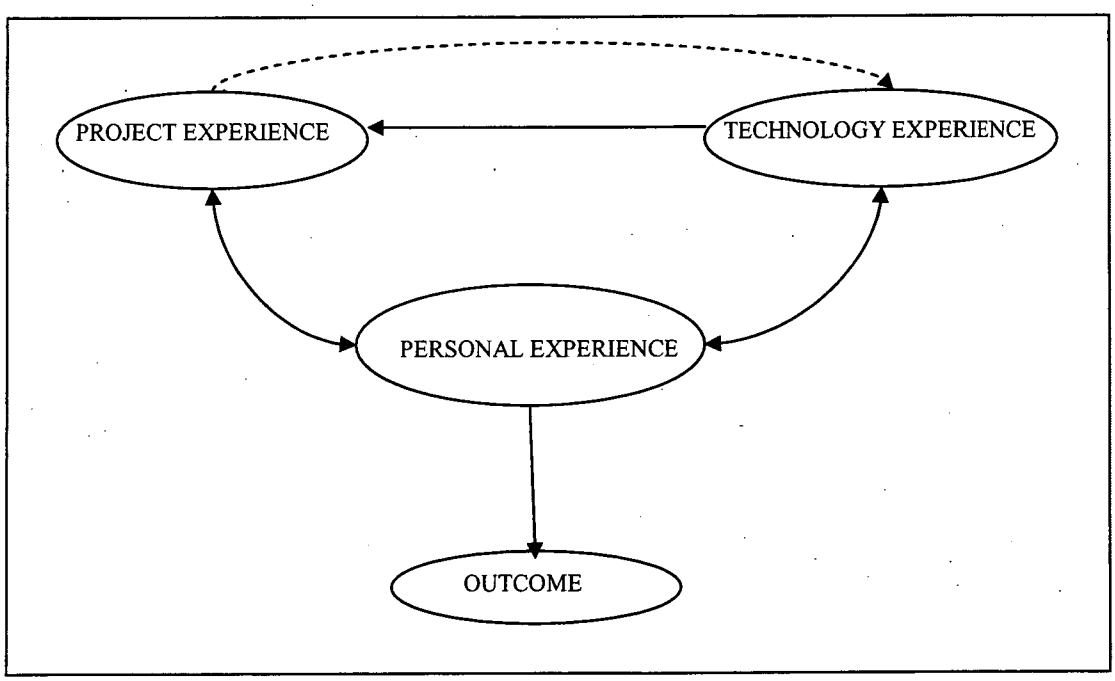

Figure 6.5: Relationships between Core Categories

This section has explained the relationships between the core categories that emerged from the triad interview analysis. These relationships are represented in Figure 6.5 above.

The next section will investigate the similarities and differences between the cases within the IT group and the non-IT group which emerged during the triad interview analysis process.

6.4 Cross Group Analysis

Through the analysis process it has become evident that there are many similarities and differences between the cases and within the groups; some of these were identified in the previous section (section 6.3).

For the purposes of this investigation the cases have been grouped into non-IT and IT groups and the comments within the axial codes have been expressed as positive or negative comments. This was not done for the core category PERSONAL EXPERIENCE as it was deemed to be adding an additional layer of researcher subjectivity to determine if a personal experience that relates to actions prior to or not associated with the intervention is judged to be positive or negative. Thus the axial codes within the core category PERSONAL EXPERIENCE were only identified as being present or not for each triad interviewee. This data is represented in Figure 6.6 below (additional version in Appendix 10). This will be discussed in terms of each of the four core categories.

PERSONAL EXPERIENCE

Within the category it is particularly noticeable that the axial code *HEALTH SYSTEM* is related only to cases B, E, J and K. This may be due to the fact that they alone have experienced problems with communication between different people/parts of the health system or it may be that their experiences have been more recent or more pronounced or it may be that they have a greater awareness of the impact of the health system upon their health care.

The other code within this core category that displays a major difference is that of support mechanisms. Only cases B, C, D, J, K and L discuss this code and for cases C and D this is limited to the mentor interview. Cases J and L have the strongest references to *SUPPORT MECHANISMS* and they are the only cases where the discussion relates to disease specific support groups and activities.

OUTCOME

Positive comments for the code *DIARY OUTCOME* are confined to Cases B, D, J and L all of whom were members of the IT case group. This is possibly due to the use of the online patient diary, however, as case B rejected the online patient diary but continued to use the paper version of the diary and found this helpful there may be other factors at play. All of these four cases had quite advanced COPD and had had the illness for a long period of time and this may have also been a factor in their positive opinion of the diary outcome. All the remaining cases (A, C, E, F, G, H, I and K) were quite negative about the diary outcome.

In relation to the code *HEALTH KNOWLEDGE* cases B, D, H, J, K and L all had positive comments. In Case E both the participant and the research assistant made negative comments but the mentor thought that there was a positive gain.

Cases A, H, C and E expressed quite negative comments in relation to the code project impact. Interestingly in cases E and H the mentors were quite positive.

Within the code *SELF-MANAGEMENT BEHAVIOUR* cases B, D, E, F, I, J, K and L all expressed positive comments. However, in cases E, F and I these positive comments were solely attributable to the mentor and not reflected by the participant or the research assistant. So the strongly positive cases in relation to *SELF-MANAGEMENT BEHAVIOUR* were cases B, D, J, K and L. Of these remaining cases all, with the

exception of case K were from the IT case group. The relationship between *SELF-MANAGEMENT BEHAVIOUR* and the IT case group is one worthy of further exploration.

In relation to *SELF-MANAGEMENT KNOWLEDGE* only case J commented here and this appears to indicate that Janice has reached a level of self-management that is not evident in the other cases and this is confirmed by the other triad members. This was previously discussed in section 6.2.2.2.

PROJECT EXPERIENCE

The attitude of cases A, C, E, F, G, H, I and K to the feedback loop of codes *DIARY FEEDBACK, DIARY USE* and *SYMPTOM MONITORING* was very negative. In contrast case B, D, J and L, all in the IT group, had much more positive attitudes. This could be a result of the use of the online patient diary or may be due to differences in understanding of the operation of this feedback loop or the result of structural differences between the cases.

All cases where reference was made to the code *GOAL SETTING* expressed a negative option, with the exception of the Edward's mentor. This may be due to poor understanding of the reasons behind the goal setting or due to poor experiences with the process. Cases J and L expressed an understanding of the theory of goal setting but both expressed the opinion that they did not find it useful. This is interesting given the importance of goal setting in self-management (section 3.3.3) and the fact that both of these participants demonstrated positive self-management behaviour. However, the second part of the feedback loop related to the goal setting involves the code *MENTORING PROCESS*. The participants in all cases and the mentors in most expressed positive responses regarding the mentoring process. Interestingly these positives were more in relation to the social contact that was experienced through the mentoring process rather than in relation to the process of encouraging the development of self-efficacy. The mentor in case A considered that the mentoring process in this case was very negative for both the participant and the mentor.

There were mixed responses within the code *PROJECT IMPRESSION*. Cases B, D, J, K and L the majority of responses from members of the triads were positive. In cases A, C, E, F, G, H and I the participants all expressed negative comments whereas the mentors for these cases were essentially positive.

The responses of cases B J, K and L regarding project knowledge imply that these cases had a good knowledge of the project. Essentially the responses from the other cases towards project knowledge were negative. This may be due to the complexity of the project or due to poor explanation of the processes.

In relation to the code *PROJECT REASON* cases B, D, J, K and L provided essentially positive responses. However, cases D and J offered some negative comments as well. Most cases decided to participate in the project for altruistic reasons with very few cases anticipating personal benefit. This is interesting as it indicates that the participants probably had little understanding of the purpose of the project when they enrolled.

TECHNOLOGY EXPERIENCE

The majority of codes within the core category TECHNOLOGY EXPERIENCE are limited to the IT case group. Cases C, D, E, J and L all reported good experiences with the IT but this did not necessarily correspond with a positive project experience

or positive outcome. Cases D, J and L had overall positive experiences. Case C reported a good IT experience because she gained the ability to play games and potentially gained status as her family visited to use the computer. However, she did not regularly use the online patient diary.

Case E had quite positive computer experience but this certainly did not lead to a positive project experience nor convert to positive outcome.

In contrast Case B reported a bad IT impact and completely rejected both the project online patient diary and any use of the computer but reported an overall good project experience and positive project outcome.

Case H wanted to use computer but did not have the required infrastructure and was not prepared to cover the cost of a landline. This meant that he could not have a computer installed and so could not use the online patient diary.

Cases C, D, E, J and L all reported that they used or intended to use the computer for purposes other than just the project.

Axial Codes	Non-IT Group																		IT Group																		Core Categories
	Case A			Case F			Case G			Case H			Case I			Case K			Case B			Case C			Case D			Case E			Case J			Case L			
	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	
Health Behaviour	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Personal Experience
Health General	✓	✓		✓			✓		✓										✓			✓	✓					✓			✓			✓				
Health Impact	✓	✓	✓	✓			✓	✓		✓	✓								✓			✓	✓					✓			✓			✓				
Health System																✓	✓		✓									✓		✓	✓							
Health Understanding		✓	✓	✓	✓	✓		✓		✓	✓			✓		✓	✓	✓	✓	✓		✓	✓			✓			✓		✓	✓	✓		✓	✓		
Support Mechanisms																✓			✓				✓			✓						✓	✓	✓	✓	✓		
Diary Outcome	-			-			-			-			-			-			+			-			+			-			+			+	+		Outcome
Health Knowledge		-								+	+					+	+	+	+	+			-			+			-	+	-	+	+		+	+	+	
Project Impact	-	-	-	-	+	+	+	+	±	-	+	-	+	+	+	+	+	+	+	+	+	-	±	-	+	+	+	-	+	-	+	+	+	+	+	+	
Self-management Behaviour		-	-		+									+		+	+		+	+	+	-	-		+	+			+		+	+	+	+	+		
Self-management Knowledge																															+	+	+				
Diary Feedback	-	+		-	+		-	+		-	+		-	+		-	+		+	+		-	+		+	+		-	+	-	+	+		+	+		Project Experience
Diary Use	-			-	-		-															-		+	+						+			+			
Goal Setting		-								-		-							-			-			-				+		-			-	-		
Mentoring Process	+	-		+						+		+				+	+	+	+			+	+		+			+	+		+	+		+	+	+	
Project Impression	-	±	-	-	+		-	+		-		-	+			+	+	+	+	+	+	-	+		+	+	+	-			+	+		+	+	+	
Project Knowledge	-	-	-	-		-	-	-	+	-		-	-	-	-	+	+	+	±	+	+	±	-	-		+		-			+	+	+	+	+	+	
Project Reason	-			-			-			-				+		+			+			-	-		±			-			±			+			
Symptom Monitoring	-			-			-			-	+		-			-	+		+	+		-			+	+		-	+		+	+		+	+		
Computer Attitude				-						+	+	+										+		+	+	+	+	±	+		+			+		+	Technology Experience
Computer Experience	-			-	-		-				-		-			-			-			+	-		-			-	-		+	-		-	-		
Computer Impact																			-	-	-	+	+	+	+	+	+	±	+	+	+	+	+	+	+	+	
Computer Initiation	-	-	-	-	-	-	-	-	-	±	±		-	-	-	-	-	-	+			+			+			+	-		+	+	+	+	+		
Computer Issue																			-			-			-						-	-		-			
Computer Rejection	-	-		-	-	-	-	-	-							-			-	-	+																
Computer Use																						+	+	+	+	+	+	+			+	+	+	+	+		

Figure 6.6: Axial Codes and Core Categories by Case Triad and Group

From this analysis it is evident that the participants hold very different views on their health and their experiences in trying to develop self-efficacy for self-management. Cases B. D, J, K and L all had positive experiences and appear to have developed the skills to assist in self-managing their condition. Of these cases D, J and L all successfully adopted and used the project online patient diary.

A number of cases had quite negative overall experiences. This was particularly evident in cases A, F and G, all were within the non-IT group.

6.4.1 Limitations

One problem/limitation of the data collection techniques used was the requirement for retrospective opinions to be gathered at interview. This is difficult for people given the duration of the study. It is difficult to remember a degree of understanding or acceptance for that period of time when this is the activity that is changing. Also for the Mentors and research assistant this was difficult for them to identify as they were exposed to so many people during the intervening period.

6.5 Reflections

This chapter has provided an in-depth discussion of the coding process involved in the analysis of the triad interviews. The core categories are explored in detail and the relationships between the core categories are identified. Finally a cross group analysis of the triad interview data is presented to determine similarities and differences between the two groups included in the research, those who adopted the online patient diary and those who did not.

The next chapter will use individual case studies to further explore the relationships between the core categories and relate these to the other individual case trial data. This further stage of analysis is to provide a picture of the case "outliers" and to further explore the emerging factors that provide for a positive project experience, with particular reference to the role of the online patient diary within these relationships.

Chapter 7 Individual Case Study Analysis

> Too often, a patient's treatments are performed "by the book" rather than being tailored to the patient's specific needs. To put it more bluntly, much of the care that today's patients receive is "medicine by numbers," which is best suited for that mythical abstraction, the "statistically average patient." (Schneider & Lane, 2005, p. iv)

7.1 Introduction

The development of the individual case studies forms a core part of addressing the second research objective of the second research question:

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO2 To explore the wider influence of the online patient diary on individual patients' experiences through an holistic examination of factors and their interactions revealed by both the clinical trial and qualitative data.

Through the combining of multiple data types from multiple data sources, including those collected over the full period of participation in the trial, it is possible to develop up a more comprehensive and complete picture of each individual participant and how their lives have both influenced and been influenced by their participation in the trial. This then enables a wider understanding of the influence of the online patient diary to be developed within the context of the individual participant's life. This depth of understanding of the interplay of factors influencing the participants' experiences is not possible through other analysis methods. It is also enhance by the availability of the multiple data sets.

This chapter provides three exemplars of the individual case studies developed as the result of the data analysis. The case studies were developed using all available sources of data including:

- the quantitative trial data;
- the triad interview data;
- records of each participant's diaries;
- diary entry data;
- data on every contact the participant had with the research team; and
- field notes and observations collected during direct interactions with the participants, their families, their mentors and the research assistant.

The three exemplars presented were selected to represent the following perspectives:

- a non-IT user with no benefit from the trial;
- an IT rejecter who gained benefit from the trial; and
- an IT user who gained benefit from the trial.

Each case study is presented in the following manner:

- Firstly the participant is described using the demographics data;
- The clinical outcome data is analysed for the individual and in relation to the same data for the relevant groups as presented in chapter 5;
- The self-reported survey data is analysed in terms of the individual and then compared with the same data for the relevant groups as presented in chapter 5;
- All the participant's contacts with the project team and descriptions of the triad are provided;
- Analysis of the triad interviews in relation to the core categories that emerged during the coding process (section 4.6.2.1) is presented;
- Each case is concluded with a reflection upon the individual case, and what it means in terms of the research questions and research objectives.

The chapter concludes with a reflection upon the case studies and the insights gained through the process of analysing these cases.

7.2 Case A (Albert)

A comprehensive analysis of data specific to Albert is presented in this section. These data have been collected and analysed as described in chapter 4.

7.2.1 Introducing Albert

Albert is a 79 year old married male who lives at home with his wife in a rural community. He was 76 at the time he was enrolled in the Pathways Home Project which means he was one of the older participants in the project and above the 75th centile for age. He is one of two married males in the case research group. Albert's highest education level was completion of year 7-10 this is in common with 58% of all participants and 75% of the case group. Albert's demographic details are compared with other members of the case research group in section 4.5.2.1 Table 4.1.

Albert has two sons who live near by. His mother-in-law lives next door and he has lived in this rural community all his life, so he has close family and community support. His sons regularly visit and help out with chores around the house. Albert is one of three participants from this postcode enrolled in the Pathways Home Project and the only one in the case research group.

Albert started smoking at 15 years of age and ceased at age 71. During this period his self-reported average cigarette consumption was 20 per day. Albert states he was diagnosed with COPD during the hospitalisation when he was recruited into the trial. It appears that he had previously been diagnosed with COPD but that Albert had not taken in this diagnosis. He had no further hospital admissions for COPD during the twelve months on the trial. Albert does not attribute his COPD to his smoking but primarily blames it upon his work environment where he was exposed to various chemicals and pesticides.

Albert's immediate history prior to his admission to hospital was that he had a sore chest and cough. After a few days he went to the doctor and collapsed in the waiting room. He was transferred to hospital by ambulance and was admitted to the intensive care unit on 03/08/2005. Albert required an emergency tracheostomy and was

ventilated for eight days. Albert was hospitalised for 26 days and was recruited into the trial on the last day of his hospitalisation.

7.2.2 Clinical Scores

This section presents an analysis of each of the clinical indicator scores measured for Albert at quarterly intervals. The measures used are explained in depth in section 2.5.1 and the method of analysis is described in section 4.5.1. A tabular representation of these data is presented in Table 7.2.

7.2.2.1 Mini Mental State Examination Scores

When he commenced participation in the trial Albert had a low mini-mental score of 23 which is on the low end of borderline. This is not unusual given the severity of the exacerbation with which he was hospitalised. During an acute exacerbation of COPD people commonly experience a degree of hypoxia which can result in temporary decrease in cognitive functioning.

Albert's mini-mental scores did fluctuate over his period of participation in the trial, however, all subsequent scores were within the normal range of 27-30. This indicates that he has no cognitive impairment.

7.2.2.2 Weight

Albert was overweight at enrolment with a body mass index (BMI) of 34. He experienced a steady weight increase over the period of participation. A weight increase of 11.7 kgs was experienced over the year which may be a concern in regard to general health indicators. However, for people with COPD being overweight is less risk for increased morbidity or mortality than being underweight.

7.2.2.3 Spirometry

Albert's percent predicted FEV1 was consistently greater than 50% but less than 80%. This classified him in the moderate COPD category. His percent predicted FEF 25-75 results were lower and demonstrated progressive deterioration; this indicates deterioration in his small airways. In contrast his FEV1/FVC ratio is 0.7 or greater for the duration of the trial. This equates to mild COPD only being present. However, it is evident through the spirometry results that Albert suffered a deterioration of his respiratory function over the course of the twelve month period.

Albert's percent predicted FEV1 and percent predicted FEF25-75 scores are significantly better than the mean scores for the intervention group, the non-IT users group and the non-IT cases group. This indicates that his COPD is milder than most other participants in the trial despite the severity of his initial condition.

7.2.2.4 Modified Medical Research Council Dyspnoea Scale

Albert's MRC dyspnoea rate has increased by one grade over the twelve month period. This indicates that the degree of breathlessness he experiences has increased. Albert's dyspnoea score is above the mean for the intervention group, the non-IT users group and the non-IT cases group. The exception to this is at the enrolment point where his scores are similar to the mean. These results are interesting as he does

not indicate his breathing as being a limiting factor in his life. The results do however confirm the decline noted in the spirometry results over the twelve month period.

Table 7.1 Albert Clinical Scores

				Interview 14/09/2006	
	Enrolment	3 months	6 months	9 months	12 months
Data collection dates	29/08/2005	7/12/2005	8/03/2006	23/05/2006	5/09/2006
Mini Mental Score	23	30	28	27	27
Weight	108.1	113	116.4	117.3	119.8
Spirometry					
Percent Predicted FEV1	56	65	61	62	56
Percent Predicted FVC	58	68	65	65	61
Percent Predicted FEF 25 75	44	41	36	36	31
FEV1 FVC Ratio	0.72	0.73	0.72	0.73	0.7
MMRC Dyspnea Scale	3	4	4	4	4

7.2.3 Self-Reported Survey Scores

This section presents an analysis of each of the self-reported survey scores measured for Albert. The measures used are explained in depth in section 2.5.2 and the method of analysis is described in section 4.5.2. A tabular representation of these data is presented in table 7.3.

7.2.3.1 Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale

Each item in the Stanford self-efficacy scale is measured on a scale of 1 to 10, with higher scores indicating higher self-efficacy. Each of the items in this scale measures a person's self-efficacy for a specific activity. Each item is explained in more detail in section 2.5.2.1. The actual score used to determine a fluctuation in the level of self-efficacy for managing chronic disease is the mean of the six item scores.

Albert's mean scores indicate a rapid increase, of 4 points, in his self-efficacy to manage his chronic condition between his enrolment in the project and the three month measure. This self-efficacy then stabilised prior to a tapering off at the final measure. It is evident that Albert feels confident that he can self-manage his condition and respond to changes.

When compared with the intervention, all non-IT users and non-IT cases groups Albert's scores commenced lower but rapidly rose above all three groups. His scores continued to be higher than all these groups until the final data collection point when they dropped below all groups.

7.2.3.2 SF36v2

The SF36v2 survey is a universally used, non-disease specific measure of health related quality of life. It is described in more detail in section 2.5.2.2. For the purposes of describing Albert's health related quality of life the physical component summary (PCS) and the mental component summary (MCS) only are presented here. Higher scores indicate better health status.

Albert's PCS scores are consistently below the mean scores for the intervention, all non-IT users and non-IT case groups. These consistently low scores on physical

functioning indicate that there is an impairment of his general health but fails to confirm that this impact is directly related to his COPD.

Albert's MCS scores follow a similar trend to his PCS scores being below those of the intervention, all non-IT users and non-IT case groups at all points except the 9 month measure. There is a significant rise in Albert's MCS score at the 9 months measure to greater than the mean measures for each of the groups. This increase is followed by a decrease at the final measure to well below the groups. These changes are not reflected in the HADS scores except in a slight decrease in the anxiety score at the 9 months measure.

7.2.3.3 Hospital Anxiety and Depression Scale

The hospital anxiety and depression scale (HADS) is measured on a scale of 1-20 with a lower score indicating lower levels of anxiety or depression, further description of the HADS survey is contained in section 2.5.2, with details of analysis in sections 4.6.1 and 5.5.3.

Albert's HADS scores, with the exception of his enrolment anxiety score, are within normal limits. Each of Albert's anxiety scores was below those for the intervention, all non-IT users and non-IT case groups.

Albert's depression scores are below those in the intervention, all non-IT users at all points. His depression scores were also below those of the non-IT case groups until the 9 month measure when it increased to be above that of the non-IT group and remained above at the final measure also. Interestingly this increase in the depression score conflicts with the SF36v2 MCS score for this period.

Table 7.2 Albert Self-Reported Scores

				Interview 14/09/2006	
	Enrolment	3 months	6 months	9 months	12 months
Data collection dates	29/08/2005	7/12/2005	8/03/2006	23/05/2006	5/09/2006
Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale					
Mean	3.83	7.83	7.50	7.67	5.67
SF36v2					
PCS	28.44	29.68	26.83	26.85	31.15
MCS	27.15	40.01	37.85	57.44	31.60
HADS					
Anxiety	8	5	7	4	5
Depression	5	3	2	4	5

7.2.3.4 Summary

The previous sections have described the clinical and self-reported scores for Albert and compared these data with the intervention, all non-IT users and non-IT case groups within this study. This has identified points where Albert's status differed from these groups but these data fail to allow us to determine why these differences occurred and the impact they had upon Albert's experiences within the project and his life in general. These data reflect what changes occurred, and when, but fail to reveal how and why they occurred.

The next sections will provide some insights into the issues of why and how these changes occurred and explore Albert's experiences within the trial in greater detail.

7.2.4 Project Interaction

In order to explore in greater detail Albert's experiences over the duration of his participation in the project it is important to place some context around it. All the data presented above was collected as snapshots on particular days approximately three months apart. These interactions occurred with the research assistant. Usually these interactions were booked well ahead and only occurred if the participant was feeling well enough. This is laudable in terms of humanity but means that there is a failure to capture data independent of the person's health status.

To examine Albert's experiences in more detail his daily diary scores were examined to identify trends and points of variation. These points of variation were examined in relation to the mentor and other health professional contacts.

Albert was asked by both his mentor and the research assistant if he was interested in using a computer to enter his daily diary but he refused the offer. He continued to complete paper diaries every day and send them in to the project office for entry to the database for 54 weeks. He received a paper record of the longitudinal diary data for the period he was involved in the trial. Albert commented in his diary on the 24/04/2006 that the "feedback easy to understand. Not particularly helpful".

An extract of diary entries for Albert is provided in Table 7.3 below.

Table 7.3: Albert Daily Diary Excerpt.

BREATHLESSNESS	COUGH	SPUTUM	FEEL	ACTIVITY	MEDICATION	DIARY COMMENTS
Slightly Better	Moderately Better	Moderately Better	Moderately Better	No Change from Normal	No Change from Normal	N/R
Slightly Better	Moderately Better	Moderately Better	Moderately Better	No Change from Normal	No Change from Normal	N/R
Slightly Better	Slightly Better	Slightly Better	Moderately Better	No Change from Normal	No Change from Normal	Pruning garden shrubs
Slightly Better	Slightly Better	Slightly Better	Moderately Better	No Change from Normal	No Change from Normal	Pruning garden shrubs
Slightly Better	Slightly Better	Slightly Better	Moderately Better	No Change from Normal	No Change from Normal	Pruning garden shrubs
Slightly Better	Slightly Better	Slightly Better	Moderately Better	No Change from Normal	No Change from Normal	Pruning garden shrubs
Slightly Better	Slightly Worse	Slightly Worse	Moderately Better	No Change from Normal	No Change from Normal	N/R
Slightly Better	Slightly Worse	Slightly Worse	Moderately Better	No Change from Normal	No Change from Normal	N/R
Slightly Better	Slightly Better	Slightly Better	Moderately Better	No Change from Normal	No Change from Normal	N/R
Slightly Better	Slightly Better	No Change from Normal	Slightly Better	No Change from Normal	No Change from Normal	Pruning garden shrubs 2 hrs

From this extract it is evident that Albert did not recognise a decline in his condition, nor did he attend his doctor or contact a health care professional. Albert uses the diary comments for basic information but there is little there to act as a trigger for him to recognise patterns of behaviour or relationships between activities and changes in his condition. This lack of insight into the deterioration in his condition does not reflect

the increased self-efficacy for self-management scores recorded above in section 7.2.3.1.

During the twelve month period Albert recorded 6 visits to his GP and 8 visits from Community Health Nurses (CHNs). The visits from CHNs occurred soon after he was discharged home and were related to changing the dressing on his tracheostomy site. Interestingly he also recorded two changes of inhaled respiratory medications, in the comments section of his diary, but did not record any associated GP or hospital visits at any point in the three weeks either side of the entries.

Albert had contact with his mentor on eleven occasions during the trial. There were two long periods when there was no contact. Albert's mentor found it quite difficult to get him enthusiastic about the mentoring processes. She also reported that he was uncomfortable with using the telephone.

Table 7.4: Albert Pathways Home Project Interactions

	Enrolled																										
Month	29/08/05	09/2005					10/2005					11/2005					12/2005				01/2006					02/2006		
Week Number		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Mentor Contact		✓		✓	✓	✓					✓					✓											✓	
Data Collection	✓																✓											
Diary Paper		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Diary IT																												

																											Interview 14/09/2006
Month	03/2006					04/2006					05/2006					06/2006				07/2006			08/2006					
Week Number	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	
Mentor Contact						✓									✓				✓					✓				
Data Collection		✓										✓														✓		
Diary Paper	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Diary IT																												

7.2.5 Albert Triad Interviews

As discussed in section 4.5.2 triad interviews for each case were conducted. The core categories, codes and the method by which they were determined are described in detail in section 4.6.2 and chapter 6. The codes identified for each interviewee in the triad for Albert are discussed in detail under each of the relevant core categories. These codes and the associated core categories are indicated in the appropriate column in Table 7.5.

7.2.5.1 Albert's Mentor

Albert's primary mentor was located at the Huon Community Health Centre where she has worked for 3 years. This mentor undertook training as one of the mentor advisors for that region. This participant was her first experience with mentoring participants within the Pathways Home project. The mentor was quite experienced with computers and expressed no concerns regarding their use within the project.

Albert's mentor did express some concerns regarding the process of phone mentoring and the lack of face-to-face contact with the participants. With Albert this concern became such that the mentor initiated a face-to-face visit approximately half way through his participation period. However, she found that this meeting made minimal

difference to Albert's engagement with the mentoring processes and the trial as a whole.

Mentoring Albert to achieve an increased self-efficacy for managing his chronic illness has been particularly difficult. He reported that he was involved in the trial just to help the researchers, not with a vision towards personal gain. As a result trying to facilitate any changes to lifestyle were difficult as his engagement was poor. Initially Albert's mentor questioned whether the difficulty engaging with him was a result of her own mentoring skills but she has since realised that it was more to do with Albert's attitude than any flaw with her skills.

7.2.5.2 The Research Assistant

The research assistant also reported significant difficulties with Albert. Although he was a pleasant man he she found that he did not engage with the trial. She also considered that he was very unsure about the interrelationships between the different elements of the trial. She reported that she had to remind him why she was there. He did not discuss the trial with her and would spend most of his time talking about his problems with his knees.

7.2.5.3 Interview Codes

Using the codes and core categories from the trial interview analysis from chapter 6 the following picture of Albert appears. A marking represents one or more comments in relation to the axial code. In core categories of OUTCOME, PROJECT EXPERIENCE and TECHNOLOGY EXPERIENCE the comments have been expressed as positive (+) or negative (-) comments. However, for the core category PERSONAL EXPERIENCE they are only marked as present (✓) or absent (no marking) to prevent excess subjectivity.

Table 7.5: Albert Triad Interview Codes

Axial Codes	Case A			Core Categories
	P	M	RA	
Health Behaviour	✓	✓	✓	Personal Experience
Health General	✓	✓		
Health Impact	✓	✓	✓	
Health System				
Health Understanding		✓	✓	
Support Mechanisms				
Diary Outcome	-			Outcome
Health Knowledge		-		
Project Impact	-	-	-	
Self-management Behaviour		-	-	
Self-management Knowledge				
Diary Feedback	-	+		Project Experience
Diary Use	-			
Goal Setting		-		
Mentoring Process	+	-		
Project Impression	-	±	-	
Project Knowledge	-	-	-	
Project Reason	-			
Symptom Monitoring	-			
Computer Attitude				Technology Experience
Computer Experience	-			
Computer Impact				
Computer Initiation	-	-	-	
Computer Issue				
Computer Rejection	-	-		
Computer Use				

7.2.5.4 Personal Experience

Albert views his COPD as an acute illness as he has only had one hospitalisation with this disease and this was an extremely serious acute episode requiring admission to the intensive care unit. He appears to have failed to realise that he has a chronic illness and so has not adjusted his behaviour to this illness. This attitude is reflected in the comments of both the mentor and the research assistant.

> He didn't have a medical problem related to that (his breathing). So, because it wasn't in his background, and it was a new thing, he couldn't see and still, I guess, can't see a bigger picture, and quite frankly if I were in his shoes I wouldn't either (Albert's Mentor).

> Look I think he was one of those who kept saying "I'm fine, I'm fine" and didn't really think that he needed it, that there was anything to worry about (Albert's RA).

> He doesn't see it as a problem, like I said before he didn't see it because nothing had happened to him before and nothing had happened to him since.

> He's got a few mild symptoms that he would just deal with it but he is not psychologically labelling it anything and why should he really at this point? (Albert's Mentor)

During the interview Albert had very productive cough, classic for those suffering COPD, but he put it down as "I get a bit croupy occasionally don't take any notice of that". He did not associate it as a symptom of what we were discussing. To him this was no problem.

> It's from when they cut me throat open. I might not have it for a few days and then it'll come back again (Albert).

Albert has suffered from "sore knees" for a long period of time. He rationalises all his health problems as being a result of his bad knees.

> But getting people to understand that me legs are no good has been my biggest problem (Albert)

> I don't know really. I think what stuffed the whole thing up really as far as I'm concerned is that I couldn't move around to do things which I tried to explain to them in the hospital. they thought, told me I'd be able to do this and do that and I said I'll tell you now I can't because the legs have been gradually getting worse for 4 or 5 years (Albert).

7.2.5.5 Outcome

Despite continuing to complete a diary every day Albert found no benefit from this.

> I never got anything out of it the diaries but I don't put down how I felt at the time. You'd have the odd day when you didn't feel so good like anybody does but most of the time I feel reasonable (Albert)

However, Albert thinks he has a reasonable understanding of his symptoms. There is some indication here that he may recognise the impact of one problem upon the other but he has an expectation that other people should do something about it.

> No I'm fully aware of where I'm at as far as breathing's concerned I know its I think when I came out I was 75% and I knew I didn't think I was going to improve much if any (cough) but well half it, no two parts of it is the trouble with my legs which I couldn't convince anybody after to listen to me and not that they'd have worked so I've put on weight (Albert)

Albert demonstrated a poor understanding of the concept of self-management. He continued to consider himself as isolated from his health care.

> You know she had plenty of ideas about what she thought I could have a go at and if I was able to do it I'd do it. So there are a heck of a lot of things you could do if you could walk (Albert).

The triad all agreed that Albert had no positive health outcome from his participation in the Pathways home Project. In fact it is difficult any positive gain he has made through his involvement.

> And ah as far as that well I could tell you people anything couldn't I? If I wanted to tell lies I could tell lies but no I can't see that I got anything out of it at all. But maybe if you people did well and good (Albert).

> I think he purely filled the forms out and spoke to me very superficially because he was doing us a favour and he may have indeed a sense of what's going on with him but I don't really know (Albert's Mentor)

> You know I think he just takes it as it comes. I don't think that he would think. In my impression is that he wouldn't think about preventative stuff perhaps that he it'd just be how he feels at the moment he would then deal with it. (Albert's RA)

7.2.5.6 Project Experience

Albert appears to have been less than enthusiastic about his participation in the PHP. His reasons for participation were altruistic, in that he thought that this may be of benefit to others in the future. This, and the fact that recruiting people when they are ill may not be appropriate, is evident from both Albert and his mentor's comments below.

> She (recruitment officer) asked me to be involved and I said no I couldn't be bothered first up cause I wasn't feeling all that crash hot then before I gone I said OK (Albert)

> I think he was just a floater really I didn't feel that he engaged fully 'cause from the onset it was "I'm doing this for you and this will help you" and even when I was trying to reflect back that actually this is to help him he was, no he didn't think and I've said this many times but he didn't think that he had too much dramatically wrong with him (Albert's Mentor).

When asked if he thought he would benefit from his participation he replied "No I didn't because I'm the only one that knows how I am".

Albert's understanding of the pathways home project was very process driven. It appears that he had not reached the level of understanding whereby he could see the interplay of the various facets of the project. This is not unusual within the cases examined.

> Oh just that I'd fill these forms in every week and send them up to you people on how I'd been feeling and how I felt and if I was getting better or worse or otherwise and that was it, weigh myself every week (Albert).

> No and I think he purely filled the forms out and spoke to me very superficially because he was doing us a favour and he may have indeed a sense of what's going on with him but I don't really know (Albert's Mentor).

The mentoring was treated as a completely separate part of the process and one that required the mentor to initiate care.

> No she's called occasionally but then it was we'd talk over a few things. What I should or shouldn't do and ehh then she'd give me a ring every, I don't know couple of months or so I really can't remember. No she was quite good. She was always on for trying to think of things that might help me all the time. Yeah (Albert).

When asked about the diary feedback that Albert received in hardcopy by post he said that it was easy to understand but not particularly helpful.

> No none, no it wasn't I'd be telling a lie if I said it was because I knew what I'd sent in I knew how I'd been feeling (long pause) and then you send the same thing back to me and it was of no benefit to me at all (Albert).

With the daily symptom monitoring it is difficult to get a clear picture of how well Albert associated the symptoms with any variations in his condition. At interview he

discussed that he knew how he felt but then related his problems to his problem with his legs. This was confirmed by his mentor's comments.

> I imagine if you fill out your diary for any length of time you would have to gain some self awareness of symptoms even if you don't really pay huge attention to them. He still couldn't reflect back on say for instance if he had a time you'd say according to your diary you've got more sputum. He'd be going oh no that was he'd say oh yes I had a bit of a croupy cough. But he couldn't relate the croupy cough back to an underlying lung disease it was just a croup cough (Albert's Mentor).

7.2.5.7 Technology Experience

In relation to the core category TECHNOLOGY EXPERIENCE Albert opted not to adopt the online patient diary for his diary entry. His attitude towards this is reflected in the following quotes.

> No good of bringing a computer down to me we wouldn't know how to plug it in (laugh) ... Not the least bit interested in computers ... We've got a TV in there, we've got to go and get somebody, even our grandchildren tell us how to work it. We don't know (Albert).

Albert had no previous experience with computers but has family members who have experience with computers. However, this did not influence his decision.

> I've usually got someone to help me with one if I'd been interested but I wasn't. Our grandkids are right into them and I just didn't bother. Not interested in them. I'd much rather watch a good documentary on television, which is what I do a fair bit of at the moment we've got Austar on and they've got some very interesting things on that (Albert).

This was confirmed by Albert's mentor. She reflected that when she asked if he would like to use a computer his response was "No, No definitely not." She backed this with her impressions of him:

> No, No. Just because you can't picture a man like Albert you know, age, stage, where he's at. No he was very happy in his way, he had no real need for it if you know what I mean (Albert's Mentor).

She thought that as he didn't engage with the diary then he wouldn't engage with anything else and a new technology would not be helpful solely for the purposes of the project.

> No, No and unless he could find something that he was familiar with on paper and write down that sort of thing and sending off and because he had no other reason like you could see that he had a grandchild and overseas that you could perhaps link him there but if you did this for that you know he could email and learn that way but no he really wasn't very much in that mind set that he wouldn't do that (Albert's Mentor).

7.2.6 Reflections on Albert

In terms of the symptom monitoring diary Albert completed it every day but he did not notice changes in his daily condition. He said that the feedback was easy to understand but not useful and that he worked out early on that he could cheat. However, when all the data is combined there is no evidence of him relating what he

saw in his diary to his actual condition or to any changes in health behaviour as a result of his symptom monitoring activities.

Discrepancies are evident when cross referencing the data from different sources. For example: when examining Albert's PCS scores and his MRC dyspnoea scores in conjunction with his diary entries for similar periods there is evidence of conflict. Albert records moderately better than normal scores for cough, sputum and general wellbeing and also records increased physical activity in his diary at periods where his PCS score is low and his MRC dyspnoea score increased. In addition during interview Albert implies that his COPD is not a major problem for him but rather it is his knees that limit him undertaking activities and that this is the reason he has gained so much weight. However, when completing the self-reported surveys participants are requested to do so in terms of their COPD. This provides a confusing picture.

In addition in his diaries Albert notes that he has spent hours gardening on most days. At interview he describes splitting 3 tonnes of firewood over a period of a few days. Neither of these examples seems to reflect the limitations recorded in the PCS and MRC dyspnoea scores.

Albert demonstrated a poor understanding of the trial and this impression is confirmed by both the mentor and the research assistant. He appears to have enrolled in the trial because he was asked a number of times and to help others.

Albert also demonstrated a poor understanding of his illness. He has mild to moderate COPD but has had one extremely severe exacerbation. He appears to not consider his condition to be a chronic one and also does not understand the downward trajectory of this illness.

From analysis of hospital admission data it is evident that Albert experienced two subsequent admissions to hospital in the eighteen month period post participation. These were both acute admissions with severe exacerbations with admission to intensive care and ventilation required on both occasions. The first of these admissions was for 36 days and the second only 9 days.

7.3 Case B (Beryl)

A comprehensive analysis of data specific to Beryl is presented in this section. These data have been collected and analysed as described in chapter 4.

7.3.1 Introducing Beryl

Beryl is a 60 year old married female. She lives at home with her husband in a housing commission area approximately 15 minutes drive from the city. She has lived in this house for 18 years. Beryl's highest education level was completion of year 7-10 this is in common with 58% of all participants and 75% of the case group.

Beryl has no children of her own but her husband has adult children and grandchildren from a previous marriage. His sons used to regularly visit and help out with chores around the house but they rarely do this any more. The grandchildren also used to visit frequently but these visits have also decreased.

Beryl started smoking at 12 years of age and was intending to stop smoking when discharged from hospital, when recruited into the trial. Whilst she was smoking her self-reported average cigarette consumption was 20 per day. Beryl has attempted to

cut down or stop smoking throughout the time on the project but without success. Her husband also suffers from COPD and also smokes. He has not been very supportive of either her involvement in the project or her smoking cessation. Beryl's husband, Bruce (not his real name), was hospitalised with an exacerbation of his COPD at the time that Beryl was recruited into the project. Bruce was also invited to participate in the trial but refused. He has continued to smoke inside the house throughout the period of Beryl's participation in the trial.

Beryl was first diagnosed with COPD in 2000. At the time of her enrolment into the trial Beryl reported that in the previous year she had had 2 visits to the department of emergency medicine (DEM) and also 2 hospitalisations relating to the condition. Additionally, she had 1 course of corticosteroids and 12 courses of antibiotics in the previous year. Beryl also suffers from rheumatoid arthritis for which she has regular methotrexate injections. These appear to impact on her breathing but she has difficulty getting her GP to listen to her about this. Poor communication between the hospital and her GP was evidenced by no letter from the respiratory physician being received by her GP.

7.3.2 Beryl's Clinical Scores

This section presents an analysis of each of the clinical indicator scores measured for Beryl. The measures used are explained in depth in section 2.5.1 and the method of analysis is described in section 4.5.1. A tabular representation of these data is presented in Table 7.7.

7.3.2.1 Mini Mental State Examination Scores

Beryl's mini-mental scores fluctuate over the period of her participation in the project with two scores, at 3 and 6 months, being one point below the normal range of 27-30. This indicates that she may have mild cognitive impairment.

7.3.2.2 Weight

Beryl had a moderately steady weight increase over the period of participation. At enrolment her weight was low (BMI 18) and by the 3 month period she had gained 5.4 kgs. Despite a slight weight loss at the 9 month assessment she concluded the project with a healthy weight.

7.3.2.3 Spirometry

Beryl's spirometry results are quite variable. At the time of her enrolment into the trial she had a low percent predicted FEV1 and percent predicted FEF25-75 both of which indicated severe COPD. However, there was a significant improvement in her spirometry results at the 3 month review, which placed her in the moderate category. Despite some fluctuation her subsequent results all placed her within the moderate category.

Beryl's percent predicted FEV1 and percent predicted FEF25-75 scores are lower than the mean scores for the intervention, all IT users and the IT cases groups at enrolment. However, all subsequent measurements of these values are higher than the mean scores for the intervention, all IT users and IT cases groups. This indicates that her underlying COPD is milder than most other participants in the trial.

7.3.2.4 Modified Medical Research Council Dyspnoea Scale

Beryl's MRC dyspnoea rate has fluctuated considerably over the period of her involvement in the trial. At commencement her MRC dyspnoea score was 5, which was higher than for the mean scores for the intervention, all IT users and IT cases groups at enrolment. Similarly her scores at 3 months and 12 months were higher than the mean scores for the intervention, all IT users and IT cases groups, which do not reflect the spirometry results.

Table 7.6: Beryl Clinical Indicator Scores

	Commenced using IT Tool 19/01/2006				Interview 17/07/2006
	Enrolment	3 months	6 months	9 months	12 months
Data collection dates	20/09/2005	16/12/2005	26/04/2006	26/06/2006	18/09/2006
Mini Mental Score	28	26	26	27	27
Weight	44.9	50.3	52.8	50	53.9
Spirometry					
Percent Predicted FEV1	31	74	64	70	69
Percent Predicted FVC	54	86	81	81	88
Percent Predicted FEF 25 75	10	35	25	32	25
FEV1 FVC Ratio	0.49	0.7	0.64	0.69	0.63
MMRC Dyspnea Scale	5	4	3	2	4

7.3.3 Self-Reported Survey Scores

This section presents an analysis of each of the self-reported survey scores measured for Beryl. The measures used are explained in depth in section 2.5.2 and the method of analysis is described in section 4.5.2. A tabular representation of these data is presented in Table 7.8.

7.3.3.1 Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale

Beryl's mean Stanford self-efficacy scores were consistently below the mean scores for the intervention, all IT users and IT cases groups. There is an initial rapid increase during the period from enrolment to the 3 month measure. But this was followed by a quite rapid decline over the following three months. Beryl's self-efficacy for managing her chronic disease appears lower at the completion of her twelve month involvement with the trial. However, this is not confirmed through the triad interviews. The peak in Beryl's self-efficacy score correlates with the time at which she decided to adopt the computer.

7.3.3.2 SF36v2

Beryl's PCS scores at enrolment were below the mean scores for the intervention, all IT users and IT cases groups. They rose to be above all these groups by the 3 month assessment but decreased to be below all groups at the 6 month measures. The final two measures were then above the mean scores for the intervention, all IT users and IT cases groups. This may be because she had to undertake more physical activity as her husband was ill.

Beryl's MCS scores follow a very different trajectory from her PCS scores. They commence well below the mean scores for the intervention, all IT users and IT cases

groups at all measures. The only exception was a peak at the 6 month assessment, where her score is above the means for both the all IT users and IT cases groups.

7.3.3.3 Hospital Anxiety and Depression Scale

Beryl's HADS anxiety scores are quite high with all except the 3 month assessment rating within the significant psychological morbidity range. These scores commence significantly above the mean scores for the intervention, all IT users and IT cases groups. There was an initial decrease in anxiety score at 3 months correlates with the time at which she decided that she wanted to adopt the computer, at this point her anxiety score was below the mean scores for the intervention, all IT users and IT cases groups. The last two anxiety measures were above the mean scores for the intervention, IT users and IT cases groups.

Beryl's depression score commences and concludes above the mean scores for the intervention, IT users and IT cases groups. However, during the 3, 6 and 9 month assessments it is below the mean scores for the all IT users and IT cases groups. At all times her depression score is below the significant psychological morbidity range and except at enrolment it is within the normal range.

Table 7.7: Beryl Self-Reported Survey Scores

	Commenced using IT Tool 19/01/2006				Interview 17/07/2006
	Enrolment	3 months	6 months	9 months	12 months
Data collection dates	20/09/2005	16/12/2005	26/04/2006	26/06/2006	18/09/2006
Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale					
Mean	2.5	5	3	3.33	2.33
SF36v2					
PCS	23.06	34.16	33.97	41.03	41.52
MCS	30.87	32.33	40.43	25.55	33.47
HADS					
Anxiety	16	7	10	11	11
Depression	8	4	7	5	7

7.3.3.4 Summary

The previous sections have described the clinical and self-reported scores for Beryl and compared these data with the mean scores for the intervention, all IT users and the IT cases groups within this study. It has identified where Beryl's status differs from others within these groups but these data fail to allow us to determine why these differences may have arisen and also what impact they may have had upon both Beryl's experiences within the project. The next section will provide insight into the qualitative data regarding Beryl's experiences within the trial.

7.3.4 Project Interaction

In order to examine Beryl's experiences in more detail her daily diary scores were examined to identify trends and points of variation. These points of variation were examined in relation to the mentor and other health professional contacts.

In mid December 2005 Beryl decided she would like to use a computer to enter her daily diaries online. She had a demonstration of the online patient diary on 11/01/2006. Beryl's partner was not present at the first visit, when the online patient diary was demonstrated, and Beryl was very enthusiastic about the computer and

starting to use the online patient diary. She assisted in selecting a location for the computer and freely offered conversation about the possibilities it allowed and that she was going to attend a computer course.

The installation of the computer was undertaken on 19/01/2006. Both Beryl and Bruce were present when the computer was installed. Bruce remained shut in another room whilst the installation occurred. Beryl found using the mouse quite challenging, particularly with her arthritis, so she was provided with an ergonomic trackball mouse. At the end of the first lesson she was asked to practice with the mouse by playing card games, she was also provided with a manual for the online patient diary.

Telephone contact was made with Beryl the following day to check her progress and a further visit was organised. However, Beryl cancelled the follow-up visit saying that Bruce did not want people visiting. She said she would continue with the computer herself. She did not use the online diary or the computer but continued to complete the paper diary daily for the period of the project. Table 7.8 provides a sample diary.

Table 7.8: Beryl Daily Diary Excerpt

BREATHLESSNESS	COUGH	SPUTUM	FEEL	ACTIVITY	MEDICATION	DIARY COMMENTS
Slightly Better	Moderately Better	Slightly Better	Much Better	Moderately More	Moderately Less	Fine worked 2 hours
	Moderately Better	Slightly Worse	Slightly Better	Slightly Less	Slightly More	Fine
Slightly Worse	Moderately Better	Slightly Worse	Slightly Better	Slightly Less	Moderately More	Tired
Slightly Worse	Moderately Better	Slightly Worse	Slightly Better	Moderately Less	Moderately More	Fine
Moderately Worse	Moderately Better	Slightly Worse	Moderately Better	Moderately Less	Moderately More	Feeling alright
Moderately Worse	Moderately Better	Slightly Worse	Moderately Better	Moderately Less	Moderately More	Out of breath a bit
Much Worse	Much Worse	Moderately Worse	Much Worse	Much Less	Much More	Not very well at all. Coughing, breathing and tired.
Slightly Better	Slightly Better	Slightly Worse	Moderately Better	Slightly More	Much More	Feeling a bit better. Worked 2 hours
Slightly Better	No Change from Normal	Slightly Worse	Slightly Better	Much Less	Moderately More	Tired
Slightly Better	No Change from Normal	Slightly Worse	Slightly Better	Moderately Less	Moderately More	Didn't get much sleep
Moderately Worse	Moderately Worse	Moderately Worse	Slightly Worse	Much Less	Much More	Not very well
Much Worse	Moderately Worse	Moderately Worse	Slightly Worse	Moderately Less	Much More	On medication for cold
Slightly Worse	Moderately Worse	Slightly Worse	Moderately Worse	Much Less	Moderately More	Still not feeling well

During the twelve month period Beryl recorded 27 visits to her GP and 28 visits from Community Health Nurses (CHNs). The visits from CHNs were regular ones that occurred after Bruce was diagnosed with facial cancer and then again after he had a fractured hip. This demonstrates that Beryl had some confusion with filling in the diary in relation to the visits and did not separate visits to Bruce from visits to her.

Beryl had contact with her mentor on thirty-three occasions during the trial. For most of the period of participation there was fortnightly contact. Beryl found her mentor useful and set up a good relationship with her.

Table 7.9: Beryl Pathways Home Project Interactions

	Enrolled																												
Month	19/09/05	10/2005							11/2005					12/2005					01/2006		02/2006							03/2006		
Week Number		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Mentor Contact		✓	✓	✓	✓		✓		✓		✓			✓	✓	✓		✓	✓	✓	✓	✓	✓		✓	✓			✓
Data Collection	✓														✓														
Diary Paper		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Diary IT																			ⓘ										

Month	03/2006				04/2006				05/2006				06/2006					07/2006			08/2006							09/2006		
Week Number	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52
Mentor Contact	✓	✓			✓	✓	✓		✓				✓				✓				✓		✓				✓	✓	✓
Data Collection									✓								✓											✓	
Diary Paper	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Diary IT																													

7.3.5 Beryl Triad Interviews

This section uses the axial codes and core categories from the triad interview analysis undertaken in chapter 6.

7.3.5.1 Beryl's Mentor

Beryl's primary mentor commenced the project sharing the mentoring role with a colleague. However, part way through her partner mentor left the Community Health Centre. This mentor also had a prolonged period of sick leave resulting in a period of minimal contact with Beryl. Beryl was this mentor's first participant within the Pathways Home project although she had other participants assigned quickly. This mentor had moderate experience with computers and expressed the opinion that they should be used more within the community health nurse's role.

This mentor expressed some concerns regarding the additional workload and the fact that the phone contact often was not the highest priority work. Eventually she, and her immediate work colleagues, decided to allocate regular time to the phone contacts and this appeared to work for her.

7.3.5.2 The Research Assistant

The research assistant found Beryl very welcoming when she visited. She found Bruce difficult and felt that he did not encourage Beryl with her participation in the trial. She found it quite uncomfortable in the house when Bruce was present and they had to sit in the hall to complete the spirometry and surveys.

7.3.5.3 Interview Codes

Using the codes and core categories from the trial interview analysis from chapter 6 the following picture of Beryl appears. A marking represents one or more comments in relation to the axial code. In the core categories of OUTCOME, PROJECT EXPERIENCE and TECHNOLOGY EXPERIENCE the comments have been expressed as positive (+), negative (-) and combined positive and negative (±) comments. However, for the core category PERSONAL EXPERIENCE they are only marked as present (✓) or absent (no marking) to prevent excess subjectivity.

Table 7.10: Beryl Triad Interview Codes

Axial Codes	Case B			Core Categories
	P	M	RA	
Health Behaviour	✓	✓	✓	Personal Experience
Health General	✓			
Health Impact	✓			
Health System	✓			
Health Understanding	✓	✓		
Support Mechanisms	✓			
Diary Outcome	+			Outcome
Health Knowledge	+	+		
Project Impact	+	+	+	
Self-management Behaviour	+	+	+	
Self-management Knowledge				
Diary Feedback	+	+		Project Experience
Diary Use				
Goal Setting	-			
Mentoring Process	+			
Project Impression	+	+	+	
Project Knowledge	±	+	+	
Project Reason	+			
Symptom Monitoring	+	+		
Computer Attitude				Technology Experience
Computer Experience	-			
Computer Impact	-	-	-	
Computer Initiation	+			
Computer Issue	-			
Computer Rejection	-	-	+	
Computer Use				

7.3.5.4 Personal Experience

When she commenced on the trial Beryl was very committed to giving up smoking. She had tried to give up smoking many times since her diagnosis but found it difficult, particularly as Bruce was not committed to trying to give up and would smoke in the house. Bruce also did not support her in changing her lifestyle even though he also suffers from COPD. Under the circumstances Beryl did very well and managed to cut down her smoking considerably.

> She's still down to just her two cigarettes a day and refuses to give up anymore and I'm quite happy with those and said you've done a brilliant job by cutting down and if she wants two cigarettes a day as a reward or as a calmer or a relax well or whatever then she's doing really well, especially as her husband is still smoking (Beryl's Mentor).

In general Beryl has noticed an increase in the ways in which her health affects her lifestyle. She has had to rationalise what she is doing so that she can continue to manage her health and also that of her husband.

> there's a lot I can't do that I'm used to doing - I can't split wood anymore not like I used to be able to (Beryl).

> And she's cut back her time at the, her volunteer work but she's putting in a lot longer day and went okay and that went right (Beryl's Mentor).

In terms of her participation in the trial Beryl has had little support or encouragement from her husband.

> I think he sort of he thought the whole thing was a waste of time too to be honest. So he wasn't interested (Beryl's RA).

Beryl has little social support at home. Whilst on the trial she has had to cope with supporting her husband who has suffered from multiple illnesses. She has had some support from her step-sons (always referred to as "his sons" by Beryl) but towards the end of the trial this support was minimal. This is evident from the quote below where she is talking about the difficulty she has splitting and carrying wood for the fire.

> Well at the moment I'm trying to do it myself and I'm getting awful curry cause he can't his legs go on him because he's got a broken hip he can't get the wood up the stairs (stairs at both back and front doors) or down stairs. His sons are going to come at the weekend and split some but whether they do is another thing. So I don't rely on anyone. If I can't do it myself then it gets burnt .. put on the fire the best way that it goes in (laugh/cough) (Beryl).

Beryl has a reasonably good understanding of her disease. She understands the chronic and progressive nature of her illness but does not dwell on it.

> It doesn't actually worry me I just stop and think that I know I'm not getting any better and that I'm going to get worse as I go on but I'm just trying to work around that. Not think of getting worse. I'm just going to , at the moment I'm just thinking I'm going to stay the way I am (laugh) (Beryl).

> That's the whole business but if I try to do something too quick at the because I'm on the spacer and the nebulizer and the other whatever you call it (Beryl).

Beryl does have some understanding of how external factors affect her illness and has discussed these with her mentor.

> the wind is sort of really knocking her about a bit but it makes her a bit breathless and anxious if she's cooped up inside so she goes outside and then the wind just takes her breath away so.. (Beryl's Mentor).

Beryl also suffers from arthritis for which she is prescribed a drug that she finds impacts upon her breathing. She has had difficulty explaining this to her GP and finding a balance so she only has her injection when she feels well enough.

> well after the last time I was in hospital I wasn't to have methatrex. Then as soon as I go back to her she's got me back on methatrex. and <respiratory physician> said no methatrex because it is upsetting your immune system . It's the arthritis and that but she's got me back on that, you can't tell her nothing (Beryl).

> Yeah to take to just to say what the methatrex is doing. Sometimes I get out of having it. If I don't have it I feel real good. As soon as I have one, I had one

last week and this is what's happening and I'm due for one tomorrow but I'm going to give that one a miss (Beryl).

There is evidently poor communication between the hospital and the GP. This has put Beryl in the middle and caused confusion about her treatment. Her GP is obviously very busy and is trying to balance the care required for two chronic illnesses without timely input from the specialists concerned.

> she said she hadn't heard from <respiratory physician> and when I asked him he said when I came out of hospital he sent her a report. So I don't know what's going on there (Beryl).

> No I'm pretty good with the ones at the Royal its just my own down here she just like she gives me an antibiotic when I want them and things like that but (cough) you can't sit and talk to her because she's too busy. So you've got to make a double appointment if you want to sit and talk to her and then she's looking at her watch all the time so. (laugh) (Beryl).

7.3.5.5 Outcome

Through using the diary Beryl has been able to see the effect of external things, for example Bruce's illnesses, upon her symptoms.

> Oh yeah sometimes I can see I'm alright and then sometimes I'm down and like he, in the last couple of months its been because of Bruce because he has a cancer operation for it inside his face and I think that might have upset the applecart for a couple of months sort of thing but I'm just starting to come alright now but its only just every now and again I get a bit puffy (Beryl).

She has begun to notice the differences in the efficacy of different medications and delivery techniques. She has also altered when she takes her medication.

> But it doesn't seem to me that the puffers seem to do as much for me as the spin haler. If I have one of them first thing in the morning I'm right (Beryl).

> If I have one of them first thing of a morning when I get up I'm alright. I might have to have the puffer at 4 o'clock but (Beryl).

Beryl considers that she has developed an increased knowledge of COPD through her participation. She has read more about the illness and knows what is happening.

> mainly from the program because there has been different things that I have they gave me in the hospital and that and I read all them and I know exactly what goes on with it (Beryl).

Beryl has begun to question her doctors and pushes to get the answers she requires and does modify her treatment to minimise her symptoms.

> Give me the new one any day but you see you can't ask the doctor down there about them because she says well I don't know what you're talking about. But I ended up with one. (Beryl).

> I'm only on one of them (inhaler) a day but sometimes before I go to bed I sneak another one in. Your supposed to have one of them in the morning and then the other one (different inhaler) for the rest of the day (Beryl).

Her mentor has noticed some positive changes in her self-management and in that she recognises changes through the symptom monitoring and uses these as triggers.

> Maybe her management has changed in the fact that she's more likely to go to the doctor's a bit earlier (Beryl's Mentor).

> Well my last phone call was the 22/9 was, "Did you notice any change in your symptoms?" "I noticed a change and thought how would I cope with myself, with rest and relaxation. I thought I might have to go to the doctor or hospital but it's settled." And she hasn't used a nebuliser for ages so by that she's actually managing it a little better (Beryl's Mentor).

The research assistant was positive about Beryl's self-management but considered that this was not due to the trial.

> I think she was already there, if you know what I mean with her management. ... I think she probably self-manages quite well (Beryl's RA).

7.3.5.6 Project Experience

Beryl receives her feedback quite rapidly despite using the paper diary.

> But it's pretty good darling I usually get them in on a Sunday night and I've got a return Tuesday so they're pretty good (Beryl).

She understands the diary feedback

> Yeah well each time the report comes back I just see the difference in the...from week to week and I know if it is any better or any worse (Beryl).

This mentor checks the diary feedback before calling. She finds this useful and it gives her a good indication of where there are problems

> I always look at their diaries before I actually ring them (Beryl's Mentor).

> it gives me something to say okay you weren't feeling very well oh like two weeks back or something so how did you go? And without that it's just hello, how are you going, oh I'm okay. Have you had any problems? Oh no bit breathless one time and that's it (Beryl's Mentor).

Interestingly Beryl sees the mentoring as irregular contact but this is surprising when the documented contacts are quite frequent. This leads to questions about the degree to which she understood the role of the mentor.

> No it's not often you hear from them it is only every now and then. But if I've got any problems I've only got to ring them and one of them comes anyway so you know they are there if you want them they're only a phone call away, sort of thing (Beryl).

Beryl's mentor believes she had a good understanding of project, lack of information seeking, self-management

> She seemed to know what was going on and why we were doing it. (Beryl's Mentor).

The phone is obviously a major issue for this mentor but she also recognises it as being a necessary progression towards the way they operate in future. However, it is obvious that she feels the mentoring relationship would have been different if they had more direct contact

> Uhh I still feel as though we need a bit more time first off to get know them a bit better. I still feel that as though we need a little bit longer to know them better or pop in once half way through or something yes (Beryl's Mentor).

> Oh well I only really know her to talk on the phone and when we do talk on the phone it's nice to talk and but I still feel that it would be good to know her that little bit better that both of us would probably get more out of it. But that's Community Nurses, you know we're so hands on and face to face. But I do think that we'll be phone counselling and the way that they're looking at it and you know I do think that it would work, it will work (Beryl's Mentor).

In some respects it appears that Beryl's project knowledge was poor. That may be a result of the complexity of the intervention and that she had difficulty actually articulating her understanding of the project. With further discussion it was evident that she did have a broader understanding and could associate the various processes.

> Well at the moment it's just that the only thing that I can understand is that it's got something to do with the breathing and the emphysema or lung functions anyway but that is all that I understand of it (Beryl).

Beryl was enthusiastic about the project

> But yes she was very keen on the whole thing (Beryl's RA).

Beryl felt she had a good understanding of the trial. She felt well supported by her mentor and through the trial as a whole.

> Nearly everything really it has all just there and if I want to know anything I've only got to ring <mentor> or that or get in touch with youse or that sort of thing you know it is only just the breathing and that that slows me down a bit at the moment but otherwise everything's going well. really (Beryl).

The research assistant noted that Beryl displayed a deeper understanding than is evident in many of the participants.

> Yes and I think she thinks about it too. She seems to, like she'd thought about the questionnaires. I mean she was one of those that was very quick with the questionnaires but I could see that she was really thinking about it and taking it seriously (Beryl's RA).

It does appear that the main reason that Beryl was participating was through a desire to help

> Yes I think that probably now I've finished saying that, that she was keen to any other studies that we have going to be in touch. She's already been on one of our other studies in fact two of our other studies so she takes the opportunity and she says that it you know may not help her but ... if it helps other people then she's happy to do it (Beryl's RA).

7.3.5.7 Technology Experience

Beryl wanted to use the online patient diary but she didn't like the computer. The research assistant considered this was more a result of negative pressure from Bruce than that Beryl did not have the ability to use the online patient diary.

> she wanted to take it up ... but she hated it and she just found it too difficult to deal with and I think her husband didn't like it either. And that might have been the main reason I don't know. I think that probably if she'd been left to her own devices that she would have embraced it because she does take on everything else (Beryl's RA).

> And it's such a shame. Because I think that she would have got a lot out of it and enjoyed it I think because she's bright and she yeah. I think that she really would have got a lot. What a shame (Beryl's RA).

Initially Beryl was not concerned about her ability to use the online patient diary but due to the minimal training period she received she did not manage to use it.

> Well I thought that I might have been able to handle it. But I couldn't get the diary things through each day and that and that's when I said to the other lady tell them to come and get it because it is all getting confused on me and I said I'll stick to the diaries and so she said well fair enough (Beryl).

Beryl did not spend much time playing with the computer to become familiar with it. In fact she only turned it on once or twice and experienced some difficulty at these times.

> No I tried it twice and that was it I thought nope and then what if something happens to the computer and then I'd get the diary all mixed up and I thought nup I'd rather stick with write it and post it off and then I know it is right. Rather than trying to send it off through the computer and that (Beryl).

> And then trying to put the words in the right order to get up the diary frame and I mucked up a couple of times cancelling just turned the complete computer off and that was it. No more (Beryl).

Beryl says she found nothing good about the computer and blames her age for not learning how to use the online patient diary.

> Not a solitary thing that's why I think it was a bit awkward to understand it cause I've never had to have any dealings with a computer and I'm going on for sixty and for a sixty year old to understand - learn a computer (Beryl).

When asked if she had had further training and assistance with using the computer Beryl responded:

> I wouldn't have been interested I just thought I'd try it just I thought it might have been a lot easier but nup too old and too stupid to learn one of them things (laugh) (Beryl).

Beryl does express some doubt about her decision to not persevere with the online patient diary.

> It was just I should have persevered a bit more with it but when you get a seven year old on there and says you do it this way Nan and you do it that way Nan and I ..NO (Beryl).

> Yep if I'd knew what to do with it I'd have been quite happy and I'd have kept it sort of thing you know but I don't know it was just that I just couldn't work it and that was all there was to it (Beryl).

7.3.6 Reflections on Beryl

The measured improvement in respiratory function, recorded in the spirometry and MRC scores, does not correlate well with the apparent decline in her quality of life and self-efficacy for self-management.

All Beryl's self-reported survey scores demonstrated a rapid rise in the first three months. This was probably the result of her returning to her normal condition post exacerbation. However, after the three month data collection point these scores all

decreased again. The only positive gain is demonstrated in the SF36v2 PCS score, which probably reflects the increased physical activity that Beryl undertook as Bruce became increasingly ill. The rapid peak corresponds with her decision to adopt the online patient diary. However, if this decline was the result of the adoption and her difficulty in using the computer it would not be so pronounced or ongoing.

Combined, these two observations indicate significant external pressures impacting upon her life. Through the triad interview and the associated observations it is possible to identify and understand some of the pressures. Thus it becomes evident that Beryl is under significant strain looking after herself and Bruce with little social support. The decrease in all her self-reported scores except SF36v2 PCS all correlate with the time when Bruce was diagnosed with cancer.

Also of interest is the fact that Beryl's self-efficacy for managing her chronic disease appears lower at the completion of her twelve month involvement with the trial. However, this is not confirmed through the triad interviews and so indicates that other factors must be at play.

It is evident from this case that the online patient diary can be problematic for some people. Beryl successfully used the paper diary and had a good understanding of it and her diary feedback. There were factors working against her in the adoption of the online patient diary but the problems she experienced did not detract from her overall project experience. Beryl did acknowledge that had she persevered with the computer she would probably have managed to use it. Significantly, through the process of adopting the online patient diary Beryl was exposed to additional contact with the project team. It is possible, through the initial demonstration process and follow-up visits and telephone calls, that she gained greater understanding of the intervention intention.

This case also demonstrates the importance of social support for people with chronic disease when trying to develop or maintain self-efficacy for self-management. Beryl lacks a social support network. Her main activity outside the home was voluntary work at a charity shop close to her home. She has little family support and few visitors; this is supported by the triad interviews and her daily diaries.

7.4 Case L (Lola)

A comprehensive analysis of data specific to Lola is presented in this section. These data have been collected and analysed as described in chapter 4.

7.4.1 Introducing Lola

Lola is a 59 year old divorced lady, this makes her one of the younger participants in the Pathways Home Project and the youngest involved in this research. She lives alone in a new detached housing commission unit where she has lived for 1 year. Lola's highest education level was completion of year 7-10 this is a similar level to 58% of all participants and 75% of the case group.

Lola has five daughters and one son all of whom live nearby and visit regularly. On most days Lola has at least one family member visiting and they also bring her food. One daughter regularly accompanies her on outings for shopping or visits to doctors.

Lola has 10 grandchildren and they also visit regularly and occasionally the older ones stay overnight. Lola has a sister who lives in NSW who visited twice during her period of participation in the trial. In addition, Lola has home help with her cleaning.

Lola started smoking at 15 years of age and ceased at age 50. During this period her self-reported average cigarette consumption was 50 per day. This is a very high consumption level.

Lola was diagnosed with COPD in 1997 and had no hospital admissions or DEM visits for COPD in the twelve months immediately prior to the hospitalisation when she was recruited into the trial. She had one course of antibiotics for a chest infection in the previous twelve months. Lola finds her condition quite restricting as she gets embarrassed and upset that she cannot do things as fast or for as long as she used to.

7.4.2 Clinical Scores

This section presents an analysis of each of the clinical indicator scores measured for Lola. The measures used are explained in depth in section 2.5.1 and the method of analysis is described in section 4.5.1. A tabular representation of these data specific to Lola is presented in Table 7.11.

7.4.2.1 Mini Mental State Examination Scores

Lola's mini-mental scores were within the normal rage and in fact steadily increased over the period of her participation in the trial. These results indicate that she has no evident cognitive impairment.

7.4.2.2 Weight

Lola's weight was stable throughout the period of her participation in the trial. This weight is a healthy one for a person of her size equating to a BMI of 22.

7.4.2.3 Spirometry

Lola's spirometry results are quite stable but very low. Both her FEV1 and FEF25-75 scores indicate very severe COPD. At all measurement points throughout the trial Lola's percent predicted FEV1 and percent predicted FEF25-75 were both below the means scores for the intervention, all IT users and the IT cases groups at enrolment.

7.4.2.4 Modified Medical Research Council Dyspnoea Scale

Lola's MRC dyspnoea rating increased by one grade over the twelve month period of her involvement with the trial this indicates that the degree of breathlessness she experiences has increased. Interestingly, these scores are lower than expected both from her spirometry results and when speaking with her.

Lola's MRC dyspnoea scale rating is below the mean scores for the intervention, all IT users and the IT cases groups at enrolment. This should indicate that she experiences less breathlessness than average participants in each of these groups.

Table 7.11: Lola Clinical Indicator Scores

	Commenced using IT Tool 04/10/06				Interview 28/02/07
	Enrolment	3 months	6 months	9 months	12 months
Data collection dates	19/05/2006	27/07/2006	7/11/2006	27/02/2007	26/04/2007
Mini Mental Score	27	29	29	30	30
Weight	57.3	57	58	57.8	57.7
Spirometry					
Percent Predicted FEV1	28	26	24	17	22
Percent Predicted FVC	72	87	87	62	80
Percent Predicted FEF 25 75	8	5	4	4	5
FEV1 FVC Ratio	0.33	0.24	0.21	0.21	0.24
MMRC Dyspnea Scale	2	3	3	3	3

7.4.3 Self-Reported Survey Scores

This section presents an analysis of each of the self-reported survey scores measured for Lola. The measures used are explained in depth in section 2.5.2 and the method of analysis is described in section 4.5.2. A tabular representation of these data is presented in Table 7.12.

7.4.3.1 Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale

Lola's Stanford self-efficacy scores commenced at an extremely low level and increased by 6 points over the first three months. There was a further increase at the six month measure by another point. It was between these measures that Lola decided that she would like to use the online diary tool.

At the initial measure Lola's score was more than three points below the mean scores for the intervention, all IT users and IT cases groups. After the initial assessment Lola's scores were consistently above the IT case group mean scores for this measure. However, at the 9 and 12 month points it was below the mean scores for the intervention and all IT users groups.

7.4.3.2 SF36v2

Lola's SF36v2 PCS scores at her enrolment into the trial were low and below the mean scores for the intervention, all IT users and IT cases groups. However, by the 3 month assessment they had increased to be above the mean scores for the intervention, all IT users and IT cases groups. Her PCS scores peaked at the 6 month assessment but remained above the mean scores for the intervention, all IT users and IT cases groups.

Lola's MCS scores were consistently low throughout her participation. At enrolment and at the 3 month assessment her MCS score was below the mean scores for the intervention, all IT users and IT cases groups. This score slowly increased to be above the mean scores for the all IT users and IT cases groups at both the 6 and 9 month points but then decreased quiet rapidly to be well below all groups again at the final assessment.

7.4.3.3 Hospital Anxiety and Depression Scale

Lola demonstrated consistently high anxiety scores on the HADS. From enrolment through to the 9 month assessment her anxiety scores were well above the mean scores for the intervention, all IT users and IT cases groups. At the final assessment Lola's HADS anxiety score was minimally below the mean scores for the intervention, all IT users and IT cases groups. Lola's anxiety scores for the first three assessments are within the range to be considered indicative of significant psychological morbidity, with her final two scores within the borderline range.

Lola's HADS depression score was within the borderline range for psychological morbidity at all measures except the 6 month assessment. Lola's HADS depression score was higher than the mean scores for the intervention, all IT users and IT cases groups at all assessments except the 6 month assessment. At the 6 month assessment Lola's depression score had decreased to a point where it was below the mean score for the IT case group and equal to the mean score for the all IT users group but it remained above intervention group mean score.

Table 7.12: Lola Self-Reported Survey Scores

	Commenced using IT Tool 04/10/06				Interview 28/02/07
	Enrolment	3 months	6 months	9 months	12 months
Data collection dates	19/05/2006	27/07/2006	7/11/2006	27/02/2007	26/04/2007
Stanford Self-efficacy for Managing Chronic Disease 6-Item Scale					
Mean	1	7	7.83	4.83	6
SF36v2					
PCS	27.30	43.22	44.80	39.87	40.83
MCS	29.23	35.67	41.45	41.98	28.76
HADS					
Anxiety	13	11	13	9	8
Depression	9	9	7	11	8

7.4.3.4 Summary

The previous sections have described the clinical and self-reported scores for Lola and compared these data with the mean scores for the intervention, all IT users and the IT cases groups within this study. It has identified where Lola's status differs from others within these groups but these data fail to allow us to determine why these differences may have arisen and also what impact they may have had upon both Lola's experiences within the project. The next section will provide insight into the qualitative data regarding Lola's experiences within the trial.

7.4.4 Project Interaction

In order to examine Lola's experiences in more detail her daily diary scores were examined to identify trends and points of variation. These points of variation were also examined in relation to the mentor and other health professional contacts.

Lola completed her symptom monitoring diary daily for the duration of her participation in the trial. In September 2006, after using the paper diary for four months, Lola decided that she would like to start using the online patient diary.

As per the online patient diary introduction protocol (section 2.7.1) she had a demonstration of the online patient diary on 28/09/2006. Lola was enthusiastic about the computer and starting to use the online patient diary. She had already selected a location for the computer and had enrolled to attend a computer course. She did express some concern about her ability to use the computer, but was reassured.

The installation of the computer was undertaken on 04/10/2006. Lola had invited her youngest daughter, who lives closest, to be there when the computer was installed.

Lola found using the mouse quite challenging but with encouragement, particularly from her daughter, she was soon playing solitaire on the computer. She progressed to attempting the online patient diary at this stage also. At the end of the first lesson she was confident that she would be able to enter her diary alone and was provided with a manual for the online patient diary.

Telephone contact was made with Lola the following day to check her progress and a further visit was organised for a week later. During that week Lola's progress with entering the online patient diary was monitored through the database. Lola required one further visit for reassurance the week following installation but she demonstrated she was competent with the online patient diary.

On the 22/10/2006 Lola contacted the research office very upset saying she had been fiddling and had broken the computer. A visit the next day identified that she had been investigating the control settings and had set it so she had a white font on a white background. This was fixed and she continued to use the online patient diary but required encouragement to realise that she could not break the computer in this way.

Lola continued to use the online patient diary daily for the full period of her participation in the trial and then requested to continue using it. As a result the system remains active for participants who wish to use it. An example of her diary is provided in Table 7.13.

As is evident from this extract Lola used the diary to good effect. She particularly used the comments section and it is possible to see evidence of self-management behaviour from this extract. On the third day she recognises a change in her condition and commences taking antibiotics. There was an improvement in her condition but this was not sustained so she attended her doctor and commenced steroids as well. This action is very different from her actions earlier in the trial.

During the twelve month period Lola recorded 13 visits to her GP. Lola had contact with her mentor on thirty occasions during the trial. For most of the period of participation there was fortnightly or monthly contact. Lola found her primary mentor useful and set up a good relationship with her. She did have contact on two occasions with her secondary mentor, when her primary mentor was away. These interactions were not as helpful for Lola and she became quite upset by them. After this she only had contact with her primary mentor. A record of Lola's interactions with the project is provided in Table 7.14.

Table 7.13: Lola Daily Diary Excerpt

BREATHLESSNESS	COUGH	SPUTUM	FEEL	ACTIVITY	MEDICATION	DIARY COMMENTS
Slightly Worse	No Change from Normal	No Change from Normal	Much Worse	Slightly More	No Change from Normal	Stuck here haven't heard from lady whose car i hit.Gdsns still here have to rely on someone to take them home as starting to get worn out.
Much Worse	No Change from Normal	No Change from Normal	Much Worse	Much worse	No Change from Normal	Dgt took gdsns home.Didn,t go to gym. feeling tired cold shivers down in the dumps-see what tomorrow brings.
Moderately Worse	No Change from Normal	No Change from Normal	Much Worse	Much worse	Slightly More	Nothimg changed from yesterday,sat in sun read but felt rotten.Started to take Clamoxyl tonight.
Slightly Worse	No Change from Normal	No Change from Normal	Much Worse	Much worse	Slightly More	Had breakfast in sun,chest wery sore went back to bed up at 2.30,pm bath,washing,letterbox and watered garden.Hope on right track with antibiotics.
Slightly Worse	No Change from Normal	No Change from Normal	Much Worse	Much worse	Slightly More	Still not feeling right,family came.Such an effort to put one foot in front of other.
No Change from Normal	Slightly Worse	No Change from Normal	No Change from Normal	Much worse	No Change from Normal	Went back to bed today had a good sleep starting to feel better.
No Change from Normal	Slightly Worse	No Change from Normal	Slightly Worse	Moderately Better	No Change from Normal	Had blood test as colestryl was still up. Only complaints today is cough and tiredness.
Moderately Worse	Slightly Worse	No Change from Normal	Much Worse	Moderately Better	Slightly More	Seen Dr.Bower prednisolone and more antibiotics body like a yo-yo up and down.Flu Vax.My health wasn't very good today.
Moderately Worse	Slightly Worse	No Change from Normal		Moderately Worse	Moderately Less	Walk to letterbox, weeded. Missed gym seems everything is so much harder. Helen rang.
Slightly Worse	No Change from Normal	No Change from Normal	Slightly Better	Slightly More	Slightly More	Half a Kalma got me through morning,went to sons was so relaxing. I was in the real world.

Table 7.14: Lola Pathways Home Project Interactions

	Enroled																											
Month	19/05/06	06/2006						07/2006					08/2006					09/2006				10/2006				11/2006		
Week Number		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Mentor Contact					✓		✓		✓		✓			✓	✓	✓	✓		✓		✓		✓		✓		✓	✓
Data Collection	✓											✓													✓			
Diary Paper		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓							
Diary IT																						✓	✓	✓	✓	✓	✓	✓

Month	12/2006						01/2007				02/2007		03/2007							04/2007					05/2007			
Week Number	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	
Mentor Contact		✓					✓			✓				✓	✓				✓									
Data Collection													✓												✓			
Diary Paper																												
Diary IT	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	

7.4.5 Lola Triad Interviews

As discussed in sections 4.4.2.5 and 4.5.4 triad interviews for each case were conducted. The codes identified in the triad interviews for Lola are discussed in detail under each core category. The core categories, codes and how they were determined are described in detail in section 4.5.X. These codes and the associated core categories are indicated with a tick in the appropriate column in table 7.15.

7.4.5.1 Lola's Mentor

Lola's primary mentor was located at the Clarence Community Health Centre where she had worked for 7 years. This mentor had no previous training in self-management or related concepts but she had previously mentored one participant in the Pathways Home project. She had a strong interest and has subsequently undertaken further training in this area. She had very little experience with computers and classified those experiences as bad. However, she was interested in learning to use them and could see that they will become an important part of the community health nurses' role. She found mentoring Lola easier than her previous participant.

This mentor was enthusiastic about the Pathways Home Project but found some aspects of it difficult. She expressed a preference for face-to-face contact with participants rather than telephone and she had difficulty prioritising the phone contact when her regular daily workload was high.

This mentor had low computing skills and reported that she actively avoided using a computer where possible, but through her participation in the project she reported that she had improved her computing skills greatly and had gained confidence when using a computer. She was also very enthusiastic about the online patient diary and used it prior to each contact with Lola. She found it useful that the feedback she saw on Lola's diary was up-to-date and she could track what was happening with Lola.

7.4.5.2 The Research Assistant

The research assistant found Lola very friendly when she visited. She was impressed with the change she noticed in her self-management but also expressed concern about the obvious change in Lola's condition over the duration of the trial.

7.4.5.3 Interview Codes

Using the codes and core categories from the trial interview analysis from chapter 6 the following picture of Lola appears. Table 7.15 provides a representation on the axial codes that appeared in each of the interviews within this triad. A marking represents one or more comments in relation to the axial code. In the core categories of Outcome, Project Experience and Technology Experience the comments have been expressed as positive (+), negative (-) and combined positive and negative (±) comments. However, for the core category Personal Experience they are only marked as present (✓) or absent (no marking) to prevent excess subjectivity.

Table 7.15: Lola Triad Interview Codes

Axial Codes	Case L			Core Categories
	P	M	RA	
Health Behaviour	✓	✓	✓	Personal Experience
Health General	✓			
Health Impact	✓			
Health System				
Health Understanding	✓	✓		
Support Mechanisms	✓	✓		
Diary Outcome	+	+		Outcome
Health Knowledge	+	+	+	
Project Impact	+	+	+	
Self-management Behaviour	+	+		
Self-management Knowledge				
Diary Feedback	+	+		Project Experience
Diary Use	+			
Goal Setting	-	-		
Mentoring Process	+	+	+	
Project Impression	+	+	+	
Project Knowledge	+	+	+	
Project Reason	+			
Symptom Monitoring	+	+		
Computer Attitude	+		+	Technology Experience
Computer Experience	-	-		
Computer Impact	+	+	+	
Computer Initiation	+	+		
Computer Issue	-			
Computer Rejection				
Computer Use	+	+		

7.4.5.4 Personal Experience

Lola found that her increasing respiratory illness was preventing her from enjoying the things she used to enjoy doing, particularly looking after her small garden.

> I'm trying to keep up with the garden but it's getting a bit of a struggle (Lola).

> Oh yes when you're breathless yes, yes you think why am I doing this, you know but you sit down and you recover and it's all good again (Lola).

She finds it difficult doing day to day activities because everything takes her so long and that the recovery period from activities is increasing.

> Lots of people don't understand you know. It took all day, Monday I think it was to mow the back lawn. But they don't understand well you know I got puffed out real bad. You know. (Lola).

> I've had so many appointments with the hospital and that you know, and, and some days it takes me a full day to recover. (Lola).

Lola is quite realistic about her condition and understands the limitations of what can be done medically.

> Well the doctor can't do anything anyway (Lola).

During the period of her participation in the trial Lola was undergoing a period of evaluation and pre-assessment for major lung surgery. This process was very difficult for Lola emotionally but it gave her additional cause to improve her physical activity levels by walking, which she quite enjoyed.

> Yes. It's only a maybe; you know it's nothing positive, yeah, yeah. I haven't got my hopes up, if it happens it happens and if it doesn't it doesn't (Lola).

> In the meantime it's walking; you know yeah, yeah, it's going for the walks. You know it's beautiful walking out there now. Mm yes, yes so oh well. I'll think a little outing I'm just a bit down what to do with everything (Lola).

The importance of having social support is very evident in the case of Lola. For a short period of time she had less contact with her family due to a minor family dispute. This resulted in her becoming more isolated and depressed. The positive effects of having improved social contact are reflected in these comments.

> I'd rung up and um things were really bad and she felt really terrible and depressed not that she'd say that she was depressed, she doesn't use that word. But her sister came over for a week and the difference in her because of the social and just having someone there. She had no difference in her symptoms whatsoever, she was perhaps even sicker than what she was before but because her mind was being taken off it you know she by her sister being there and having some social interaction and stuff. I rang up and I said how are you and she said oh I'm really good thank you and I nearly fell over backwards but you know that to me is something that I've always known but yeah it was just incredible to see how much of a difference it made (Lola's Mentor).

> I think the more she's out doing things and socializing and the more you know sort of bits and pieces that she's got on the go that she's doing now in her life. (Lola's Mentor)

Lola also enjoys the social contact and support she has gained through her participation in the trial.

> She seems to very much enjoy being all aspects of it really. I think she quite likes having the umm she likes talking to people and having the social side of it as well and she's up in the physio and she talks about it up there I gather because she's referred to what she's told them up there so (Lola's RA).

> I think there's a lot of social contact that these clients get is that somebody's listening to them you know and actually ringing in every two to four weeks or whatever and listening to them. I think that's made a big difference to them and to how they feel security wise yeah and probably socially (Lola's Mentor)

7.4.5.5 Outcome

Lola found using the online diary a useful tool in managing her condition. She found some release through writing the diary at the end of the day.

> Just by writing down yes, yes. Writing it down, of course it's a release, you can release it, whereas you can't talk to people, people don't understand and unless you can talk to, you know write it down and talk to a computer about it and it is a release (Lola).

Lola considers that her understanding of her illness has increased.

> Yes, yes because maybe if someone told me three years ago to exercise and walk it really does help yeah I think, I wouldn't have believed them but it does help (Lola).

Lola's management of her condition has changed through participation in the trial and she actively initiates treatment at the first sign of a change in her condition. This is often based upon noticing changes through the use of the online patient diary.

> Yes, yes, yes, that's all changed. I've got two packets of antibiotics so and antibiotics in there so if I come down with something then you know, then come tomorrow I'll know to start them (Lola).

She has also started initiating her own monitoring.

> Since I've been on the Pathways you know it's made me buy my own pedometer so I wear that every day so I've got the record from the six months from last year about how many steps I do a day. .... Yes and last week I got to 11,000 steps (Lola).

Lola's mentor considers she has good knowledge of her health and what is happening. She also wants to be more actively involved in her care than previously.

> I think she manages her COPD fairly well in comparison to a lot of other people and it's like she does push herself and she does try and she is certainly the one who is in there doing it not like most of my participants but yeah I guess that she does know because she says to me oh you know my breathing's getting worse and I must be deteriorating and I know I'm deteriorating and I know that you know (Lola's Mentor)

> I think she's taken her power back a fair bit and willing to work with that and get answers and you know and she's happy to talk to us and comfortable with ringing up or asking so I think, I think it has 'cause when I first met her she was a bit despondent about all that stuff and you know oh what's the point no-one listens to me anyway and you know like and there's nothing that can be done for me anyway and ... (Lola's Mentor).

> Yeah and I guess those sorts of things and I think you know her awareness I guess of you know the need for exercise and to get going and um to challenge herself she's certainly got on (Lola's Mentor).

Lola had previously attended a CDSM course and so was already aware of the principles of self-management.

> I do think that doing that chronic diseases course that six week program certainly gave her the understanding of before I even got there and the nature of goal setting and so on (Lola's Mentor).

7.4.5.6 Project Experience

Lola found the diary and the diary feedback useful

> Yes, yes 'cause those diaries, if I didn't write it down I wouldn't have given it a second thought about it mm yes, it sort of helps you to look after yourself and manage yourself a bit better mm. (Lola).
>
> She told me first up about the diaries is that they were very useful because she could actually look back and I think more so with Lola that was her mood states that were affecting her a lot and I think that she's actually been able to look back and how she was really feeling terrible on this day and you know wonder why, why that was happening (Lola's Mentor)
>
> I used to read them I think and I'd say to myself oh my gosh did I write that? (Lola).
>
> yep. now I think she really does. she enjoys doing that and I think she actually thinks about it and has gained quite a bit from it (Lola's RA).
>
> No she's very comprehensive with her diaries. Tells me everything that she's been up to and ... She'll certainly pull me up if she thinks that I haven't read 'em (Lola's Mentor).

Lola expects her mentor to have read her diaries and to be able to comment on them if there is something unusual. She also adds some personal notes to the project team at times and so uses the diary as a means of ongoing communication with the project team.

> last time I was reading the wrong one and I said oh um you had something or other I can't remember what it was she said NO that was like my last diary (Lola's Mentor).
>
> Yeah so she's certainly likes to know that I've read them (Lola's Mentor).

Although she understood the principle of the action planning process Lola did not think it beneficial to her but more found it limiting.

> But you know when are you going to do it? How many times are you going to do it you know. It's, It's when you want to do it, you know 'cause I think that I'm pretty, well I think that I'm pretty well self-motivated and I'll do you know what I can when I can and not out of a form saying well when are you going to do it and how many times are you going to do it? You know and I just, just and I've never liked it. (Lola).
>
> No. Only the action plan. That one, get rid of that, (Lola).

As previously noted Lola had undertaken previous group based CDSM courses and this made her more aware of the possibilities of the trial. She did find the group based course good as she had other people with her.

> I don't, I think the self-management one made me a bit more aware of the Pathways one. You know, to be a bit more open about things that were going on. Yes, yes because the self-management um was what brought me out of myself. Yes, yes, you know stick up for yourself and mm. (Lola).
>
> Well the Stanford one was where you communicated with other people and you know, you know what was going on whereas with Pathways it's only you and your computer. Yes, yes, so but as I said I go to the gym where I can communicate with the people that go to the gym so it's still the same thing. Yes, yes, mm. (Lola).

Lola experienced some difficulty with the mentoring when her mentor was away and she was unwell but found the replacement mentor unhelpful.

I should have had antibiotics here but I didn't have antibiotics here and to be sick and then to get a lecture you know (Lola).

However, she found her primary mentor excellent and the contact was very positive for her.

Oh yes oh she's marvellous. I could be down in the dumps and she could ring up and I'm not down in the dumps anymore so you know (Lola).

Lola's mentor was quite aware of the fact that she could become dependent upon her.

Lola would probably have to be one of the best one of my clients and the most active in the project and she's taken it you know like. Like if she's not going to be there she'll ring me the day before to tell me she's not going to be there and she rings in quite often and checks in with me half the time about things that I don't know about (Lola's Mentor).

So I'm having to be a bit careful. Because it is about self-efficacy I have to be careful not to 'cause I think that she could quite easily become quite dependent on having someone that she can ring up (Lola's Mentor).

Well when she first started I think she sort of thought, I mean I think she understood it was about making goals and she actually did the chronic diseases management course (Lola's Mentor).

Lola has a good understanding of the trial and could put all the processes together.

I think she has actually because just from the things she says umm she refers to how she's been when I see her and how what she has put in her diary and yeah I think she actually has gained. She has been one that has. (Lola's RA).

Lola enrolled in the trial because she thought that she would be able to benefit from it.

I got involved because that <project officer> came and seen me and I found that it was of benefit to me to be able to talk and you know write down the way I felt. Yeah yeah ... Yeah, helping me but if you get benefit out of it then good luck to you (Lola).

I think these two things (CDSM programmes) go very well hand in hand and because she had actually done that she was actually making goals and so I just piggybacked onto it. (Lola's Mentor)

Lola has found considering her symptoms when completing the diary has been useful in helping her understand when things are changing.

Yes, it makes you more aware you know of if you're not right. Yes (Lola).

7.4.5.7 Technology Experience

Prior to adopting the online patient diary Lola had no previous experience with computers.

No I didn't have. No I didn't even know how to turn one on. (Lola).

Lola chose to use the online patient diary because it was offered and she thought it would simplify things for everyone.

Well it was offered to me and I thought well if it's going to make everyone's life back where it goes, easier for them yes, yes so I might as well give it a go. You know, I can always go back to the paperwork if it doesn't work out. (Lola).

Lola had no difficulty learning to use the online patient diary.

No, I, I used to get my diary in on the first go (Lola).

Lola started doing a computer course at the time she had the computer installed. This course ended up being at the wrong level for her and led to increased anxiety levels. She chose to withdraw from the course. She did however persevere with the online patient diary with no problems.

> so that I could do a bit more but I was set back too much with the computer course. I had to take a Kalma (benzodiazepine anti-anxiety medication) before I went because I was so nervous and anxious and I'm thinking how am I going to get through it? You know, and I thought no I can't go through this stress, it's not worth going through this stress over a computer (Lola).
>
> No, no, no I don't think so. It just doesn't worry me anymore, I'm confident enough to write it down and what I'm going to put right and I sit down and I write it and then I get on the computer and do it. Yes, yes and that's it (Lola).

Lola has developed her own method of entering her diary.

> I always write down how I'm feeling on the day before I put the symptoms, yeah because if I'm worse on that day and I've had a sod of a day, well you're not going to put you know, had an awful day and then at the field, you know you put that you felt really good, you know so yeah I do the symptoms.....on my bit of paper. But on the computer I do it the right way (Lola).

Lola felt well supported through the phase when she was learning to use the online patient diary through both the project team and her daughter.

> No, no I had enough before because I had everyone's phone number to ring and Leanne, she was a great help 'cause she was good with computers so she was a great help as well. Mm, yes, yes (Lola).

Lola has become so comfortable with the computer that she takes it for granted.

> Uhmm. That's a hard one 'cause I take it for granted using it now, uuh you get to type your diary in and that's yes it's out of the way and you don't have to race for the letterbox and (Lola).

The only difficulty she finds is when something unexpected occurs.

> Oh when it mucks up. When it doesn't want to do what you want it to do. Yes you get a bit confused and yeah you walk away and try again later. Mm yeah and yeah you've got to have patience when it won't. Yeah, yes yeah mm (Lola).

Lola even made action plans about learning to use the computer which demonstrates combining the components of the trial.

> We had an action plan about the computer. Yeah she wanted to go to a computer course. So we thought that could be a good action plan so I think you got in there and brought the computer in and she hated the computer course. think she went about twice and then she just didn't go anymore and um but she still continued with the computer and learnt how to do it (Lola's Mentor).
>
> I think she does and she never complains about the computer. I think she gets up to a whole lot more than she tells me actually (Lola's Mentor).

Lola has gained a sense of achievement from using the computer.

knowing that you know at least I can do something on a computer. That's a big achievement, for me. (Lola).

She has become more relaxed about the computer and uses it for other purposes.

I'm more relaxed with it, mm, more relaxed. If something goes wrong, it goes wrong yes and I don't blame myself anymore. Like I used to mm, yes (Lola).

I play games on it. I did start up a folder of my own (with word documents) but I haven't been keeping it up (Lola).

Yes and I haven't been going back into it as I said having all these tests and you know so much do here and that, I just don't get time to sit down and do it. You know if I had more time yeah. And people say you must have lots of time but it takes me so long to do something (Lola).

I'm not scared of them no. I'll go into programs and I'll read them and I think no you don't know nothing about it and I just close it down and get out of there. Yeah so, mm. (Lola).

Lola has a routine when entering her online patient diary but she finds that she does not spend a lot of time on the computer. (Lola was interviewed in summer when the weather was good and the days long).

No, no. 'Cause I find sitting around doesn't help a bit you know so yeah, yeah. And I do my Pathways I use the same couple of games and I've had a game probably Solitaire and then turned it off so it's as I say, yeah, yeah. Oh I disconnect the Internet, phone call first yeah and then play the games so yeah. (Lola).

'Cause it would be silly being on the computer and playing games and that now when you could be outside enjoying the fresh air, you know. Maybe in wintertime it'll be different. I will be able to have more time to play with the computer. Yeah, whereas you know this weather. (Lola).

The mentor finds it a benefit to have her participants using the online patient diary.

Yeah the two that do fill in the diaries and I've got three Pathways clients left and the two that do fill in their diaries do them online now so and that really is useful because you can pick up from how they were yesterday rather than you know a week ago. And how often this was? (Lola's Mentor).

7.4.6 Reflections on Lola

There is some conflict between Lola's spirometry readings, MRC dyspnoea rating and the interview and observational data relating to her breathlessness. Lola's spirometry results demonstrate very severe COPD and this is confirmed through the interviews and observations. However, her MRC dyspnoea rating is noticeably lower than expected, particularly when compared with other cases. This may be through her underestimating her disability or because she pushed herself so hard and tried to normalise her condition.

Lola's self-efficacy for self-management scores decreased rapidly after an initial large rise. This does not correlate with the degree to which she did develop self-management behaviours. The initial increase can be accounted for in that she had returned home after an acute exacerbation and had additional attention through the trial. However, there was a further increase after the initial assessment and after she started using the online patient diary. There appears to be a degree of correlation

between her increasingly poor health, her increasing understanding of her illness and the decrease in her self-efficacy for self-management. This may indicate that as she has become sicker and understands her disease more she is less confident that she can manage her illness and its impacts, even though she demonstrates improved self-management behaviours.

Throughout the trial period most of Lola's anxiety and depression scores are within the range to be considered indicative of psychological morbidity. High levels of anxiety and depression are also evident throughout the triad interviews. Lola was evidently prescribed a benzodiazepine but there was no evidence of monitoring of her condition, or of psychological treatment being initiated through the trial. This is of concern as there are moral and ethical considerations that need to be addressed in trial design.

Lola found the diary very useful in general but once she commenced using the online patient diary she found the usefulness increased. This was because of the rapid feedback and that she could browse through and note associations between events and changes in her symptoms.

Through the combination of the online patient diary and the mentoring Lola achieved an increased level of self-management behaviour. She would initiate health interventions earlier and without first seeing her doctor. She was more confident about questioning her doctor and became more involved in her care. She also initiated investigating alternative treatment.

For Lola the introduction of the computer had both positive and negative effects. The introduction of the computer to her home and training through the trial was a positive outcome for her. The negatives were primarily associated with the computer course she enrolled in. This course was advertised as a beginners computing course but was more technical than was required and actually decreased her confidence and caused her unnecessary distress.

Lola demonstrated a very good understanding of the trial and all its processes. This level of understanding may have been due to the fact that she was enrolled by a different project officer. This project officer had identified issues with the terminology used to explain the trial and simplified the language she used when explaining the trial. Additionally, Lola is one of the few participants who identified that she entered the trial anticipating some personal gain. Once again this may be in part attributable to the change in the language used at recruitment.

Lola lives alone and through the limitations imposed by her illness she is quite isolated. The participation in this trial and the subsequent contact with the project team has evidently had an impact upon her isolation.

Lola has a lot of social support and this is very important to her in keeping her anxiety and depression in check. Interestingly when her sister was visiting Lola experienced an improvement in her depression, as noted by her mentor, but this was not evident through the symptom monitoring or at least not immediately.

Attending the gym regularly was another form of support group for Lola. It was a safe place where she could talk with people with similar problems. Additionally, through the trial her mentor was seen as a very important support mechanism.

Chapter 8 Interpretation and Discussion

You can't write all that you say

You can't say all that you know

You often don't know what you know – until you need to.

As expressed by Branko Ceznik in (Nøhr, 2007)

8.1 Introduction

This chapter provides an interpretation and discussion of the data analyses conducted in Chapters 5, 6 and 7. This discussion refers to some data revealed in the analysis of the all individual cases and not only those presented in Chapter 7. The chapter reveals key insights into the influence of an online patient diary on the health outcomes and experiences of people with chronic obstructive pulmonary disease within a mentored self-management programme. This chapter is divided into the following sections:

- Section 8.2 presents a discussion of the implications of the clinical trial data, as presented in Chapter 5, in terms of the first research objective of the first research question.
- Section 8.3 presents a discussion of the clinical trial analysis in relation to the second research objective of the first research question.
- Section 8.4 provides a summary reflection upon the clinical trial interpretation in response to the first research question.
- Section 8.5 engages in an in-depth interpretation and discussion of the findings from Chapters 6 and 7 around the first research objective of the second research question. This section focuses upon the influence of the online patient diary.
- Section 8.6 provides a discussion regarding the broader influences of the online patient diary, outside the symptom monitoring process. It is divided into five subsections each of which relates to the core findings of Chapters 6 and 7. These subsections provide an in-depth interpretation and discussion on the emergent themes of: impact of the computer, participation issues, isolation, support and the significance of illness.
- Section 8.7 reflects upon the overall impact of the online patient diary on participants' experiences within the trial.
- Section 8.8 discusses some of the broader implications of this research and reflections on how they re-contextualise approaches to CDSM involving ICTs, health outcome and IT impact evaluations, and issues related to notions of the patient as eHealth evolves.
- Section 8.9 provides a summary reflection of the key elements to emerge from this chapter.

Through the analysis of the data presented in Chapters 5, 6 and 7 a web of complex interactions have become evident. This in itself poses a major problem in how to meaningfully present this interpretation and discussion chapter.

To structure this interpretation and discussion chapter the research questions and research objectives; the qualitative core categories; the quantitative outcomes and results; and key insights beyond the specific research questions will be presented and discussed. Critically, because this involves the interaction amongst a range of factors

whose significance and influence may change across each case and within each case over time this chapter examines and discusses key insights from multiple perspectives.

8.2 Impact of the Overall Intervention

This section provides an interpretation of the findings from Chapter 5 to address the first research question and the first research objective related to it. The research question and research objectives addressed in this section are:

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

RQ1: RO1 To describe the impact of the overall intervention on health outcomes.

The clinical scores for the control and intervention groups showed minimal variation. The mini mental state examination (MMSE) scores were generally within the normal ranges over the duration of the trial. The minor increases in the mean scores can be accounted for by the effect of the acute exacerbation and hospitalisation at the time of enrolment. During an acute exacerbation there is lower blood oxygenation saturation than normal and this decreased level can lead to temporary confusion impacting upon the MMSE results.

The spirometry results also indicated little of clinical significance with the exception of providing confirmation that all participants had moderate to severe lung disease and that this appeared to improve slightly from enrolment to completion. This effect was probably due not to an actual improvement in lung function but to the fact that the initial measurements were undertaken immediately post acute exacerbation, which may have had an effect upon the results. Also the results at the enrolment include participants who withdrew or died during the participation period and this may account for the improvement of cohort results.

The Pathways Home for Respiratory Illness project was aimed at improving participants' self-efficacy to manage their COPD. This was measured using the Stanford self-efficacy scale. In terms of the development of self-efficacy for self-management there was a positive improvement for the participants within the intervention group and no effect within the control group. This appears to indicate that the intervention was successful in assisting participants to improve their self-efficacy to self-manage their COPD.

Two quality of life indicators surveys, SF36v2 and HADS, were used to evaluate the quality of life outcomes for participants within the project. The SF36v2 was explored in terms of the physical component summary and mental component summary scores. In terms of the SF36v2 PCS mean scores the intervention group experienced increased PCS scores and a small to moderate positive effect indicating an improvement in the way participants evaluated their physical condition. In the control group there was a very small decrease in the mean PCS score. This indicates that intervention has improved the physical components of participants' lives. This could be the result of the goal setting and action planning process which for many focussed upon increasing physical activity in an attempt to improve respiratory function.

In relation to the MCS scores there was an overall increase in both the control and intervention groups. The control group improvement was significantly lower than the

Clinically and in terms of lifestyle limitations Lola's condition was very severe. She had good understanding of illness and trajectory but was investigating alternatives involving major surgical interventions.

Although Lola had no hospital admissions for COPD during the twelve months of her participation in the trial she was hospitalised with an acute exacerbation almost immediately after she completed the trial participation period. Lola went on to have preliminary lung surgery in October 2007, the outcome of which has led to more severe limitation upon her activity levels. By mutual agreement Lola was removed from the active surgical treatment list as a result of this post operative deterioration. However, she does continue to attend her regular cardio-pulmonary physiotherapy classes.

7.5 Reflections

This chapter has introduced the reader to the exemplars of the individual case studies. These case studies are a complex and comprehensive combination of the data from a range of sources including quantitative trial data, the triad interview data, participant's diaries, records of contacts, and field notes and observations collected during direct interactions with the participants, their families, their mentors and the research assistant.

Through this combining of data it has been possible to identify points of similarity and conflict between these data at the level of the individual participant. Using this method it is possible to identify personal influences and reasons for the differences. This analysis has reached past a simple analysis of the initial trial data in relation to the impact of the online patient diary to provide a deeper investigation of the impact of both the project and the online patient diary tool on the participants' lives.

A number of key findings are evident from the analysis contained within this chapter. These include the finding that independent of any outcomes attributable to the online patient diary there were broader influences from the introduction of the computer. Factors such as; isolation, the presence of support mechanisms, significance of illness and perceptions of personal benefit all have significant influence upon the overall life experiences of participants in the trial.

Through the individual case studies a complex picture in terms of the adoption and subsequent use of the online patient diary has begun to emerge. This picture provides evidence that questions the simplistic assumptions of the benefits of the introduction and use of information technology solutions for people with chronic illnesses. It reveals the need to explore past the quantitative trial data when evaluating the impact of technology within trials.

The next chapter, Chapter 8, will provide an interpretation and discussion of the analysis contained within this chapter and chapters 5 and 6. The interpretation and discussion will be presented initially in relation to the research questions and then explore the relationships between factors identified.

intervention group at the final measure but interestingly was higher at each other point. All PCS and MCS scores are below the norm for these measures, which are based upon the standard SF36v2 norm based scoring from the 1998 US population data. This is not unexpected in a group of people with a long term chronic illness.

The other quality of life measure utilised was the Hospital Anxiety and Depression Scale (HADS). This measure demonstrated a significant decrease in the mean anxiety levels in the intervention group with no significant change for the control group. Similar results were evident for the depression scale with the intervention group experiencing a significant decrease, but the control group experiencing a small increase.

All quality of life measures at this stage indicate that there has been a positive impact from the intervention and that the quality of life for participants in the intervention group has improved over the duration of the project. Overall participants in the intervention group experienced positive outcomes in terms of both their development of self-efficacy for self-management and the quality of life outcome measures.

8.3 Quantitative Impact of Online Patient Diary

This section specifically addresses the second research objective relating to the first research question.

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

RQ1: RO2 To explore the impact of the online patient diary on health outcomes within the intervention.

This exploration is undertaken in terms of two different groups. Firstly, a comparison of the results from all IT users and all non-IT users within the total intervention group will be discussed. Secondly, the data relating to the two case groups, IT cases and non-IT cases, which form the core of this research. These data will be used to determine the quantitative impact of the online patient diary within the overall trial intervention and in the research sub-groups.

Studies, see for example (Karavidas, Lim, & Katsikas, 2005) and (Dyck & Smither, 1996), have indicated that computer use in the elderly is significantly influenced by gender. They found that males have greater computer knowledge, are more confident and less anxious about using computers than females. Interestingly this is not confirmed within this research data where females were much more likely to select the online patient diary option.

In terms of demographic differences between the IT users and non-IT users it appears that for the participants within the project the older age group, and particularly older males, are less likely to attempt to use the online patient diary. Those most likely to use the online patient diary are younger females.

The participants who chose to use the online patient diary were more likely to continue their involvement with the project for the complete twelve months. All non-completions in this group were deceased. A similar number of non-IT users were deceased but 77.95% of those in the non-IT group who failed to complete withdrew

from the project[7]. Educational level appears to have little impact upon the decision to use the online patient diary.

The data relating to the actual usage of the online patient diaries and the paper diaries does not provide a clear pattern of behaviour. Participants were more likely to continue to use the online patient diary than the paper diary. There was a higher mean usage in the all IT users group than in the non-IT users group. However, the non-IT case group had a higher mean use than the IT case group.

As with the clinical outcomes data in relation to the first research objective, there is no major difference to be noted between the groups in relation to the clinical outcomes.

In relation to the development of self-efficacy to self-manage their condition using the Stanford self-efficacy scale both the IT user and non-IT user groups experienced a positive improvement in their self-efficacy for self-management. However, the scores for the non-IT user group demonstrate a much greater improvement, almost double the effect size, than the IT user group. This appears to indicate that the use of the online patient diary impedes or limits the development of self-efficacy for self-management in people suffering from moderate to severe COPD. Alternatively it may indicate that those who were willing to take on change could adopt the online patient diary and develop self-efficacy but the degree of change was mediated by learning two tasks.

In terms of the quality of life measure SF36v2 the PCS effect size in each of the IT user and non-IT user groups was the same but the mean score for the IT user group was lower than that for the non-IT user group. This difference was noted at both commencement and completion which may indicate that the physical wellbeing component scores for the IT user group were lower than those for the non-IT user group. For the SF36v2 MCS scores there was an improvement in both the IT user and non-IT user groups with a slightly greater effect size in the IT user group.

In relation to the HADS survey results there was an improvement in the anxiety level for each of the IT user and non-IT user groups but this improvement was more pronounced in the non-IT user group. In the depression scale there was a greater improvement for the non-IT group with a small effect size but there was an overall lower mean depression score for the IT users than the non-IT users. This indicates that there has been some effect from the intervention in terms of the participant's anxiety and depression levels but most of these scores were below clinically significant levels throughout the project.

With respect to the two research case sub-groups the IT case group fared worse the non-IT cases in all scales. In relation to the development of self-efficacy for self-monitoring although there was an improvement in both groups, but the IT case group had a much smaller improvement than the non-IT case group. This is consistent with the results of the overall IT user and non-IT user groups.

In the SF36v2 PCS scores the effect size was smaller in the IT case group than in the non-IT case group and the mean scores were 8.77 lower at completion than those in the non-IT case group. In the MCS scores there was a significantly larger effect size

[7] The reasons for withdrawal are being explored in papers by members of the Pathways Home for Respiratory Illness research team.

in the non-IT case group than in IT case group, despite the fact that they both had large positive effects.

In relation to the HADS scores the anxiety score provided a very significant change in both the IT case group and the non-IT case group. However, regardless of this effect size the mean score in the IT case group continues to represent a borderline score for clinical anxiety. The HADS depression scores indicate that there was a significant improvement (decrease) in mean depression scores for the non-IT cases but a minor increase for the IT cases.

Overall given the results demonstrated above it is evident that the use of the online patient diary could be seen to inhibit the positive impacts of the intervention. So what are the possible explanations for these findings? The most obvious is that the online patient diary and its use in some way interferes with the process of the mentored self-management.

In terms of the Stanford self-efficacy for managing chronic disease 6-item scale the online patient diary appears to have weakened the positive effect of the intervention upon the development of participant's self-efficacy for self-management. This is possibly due to the additional learning burden of commencing to use the online patient diary. Alternatively it is possible that the participants using the online patient diary have more regular interaction with their own symptoms, through the rapid online feedback; this may have raised their awareness of the limits of their self-management skills and as a result enabled them to reflect more critically on their self-efficacy for self-management than participants in the non-IT groups. In terms of acquiring skills that will assist in self-management behaviours during a life-time it can be argued that the online patient diary may have stimulated a more realistic assessment of participants' actual skills and knowledge.

In relation to the quality of life indicators both the IT user groups commenced the project with lower mean scores on the PCS and MCS scores and both did improve but to a lesser degree than the non-IT groups. This could indicate that people with lower quality of life are more likely to adopt the online patient diary. This is consistent with people with increasing disease status becoming more isolated and through that isolation becoming more open to alternative sources of company, in this case the computer.

The alterations in the HADS scores provide a general downward trend (improvement) for all groups in the anxiety scores which is to be expected as the initial scores were recorded whist participants were hospitalised and so their anxiety levels are high. There was little difference between the groups with respect to these measures. The depression scores indicate that there was less fluctuation in the IT user and IT case groups than in the non-IT user and case groups. This may be due to the stage of the disease process and the degree to which the participants have accepted their disease trajectory.

From the trial data it appears that those participants who used the online patient diary had some improvement in their self-efficacy for self-management and quality of life scores. This effect was less than the effect noted in the whole intervention group but was greater than the control group.

8.4 Discussion on the Clinical Trial Outcomes

Sections 8.2.1 and 8.2.2 of the thesis have briefly discussed the results of the clinical trial in terms of the first research question and its associated research objectives:

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

RQ1: RO1 To describe the impact of the overall intervention on health outcomes; and

RQ1: RO2 To explore the impact of the online patient diary on health outcomes within the intervention.

Through this research it has become evident that when evaluating a chronic disease self-management intervention, involving people with a progressive chronic condition, employing clinical outcome measures such as respiratory function are not particularly useful measures of health outcomes at a cohort level. This is because these people are going to have a progressive, but unpredictable, deterioration in these measures due to the nature of their illness regardless of the intervention. Thus when combining the results from a number of participants, at different cohort or group levels, simple descriptive statistical analysis does not provide for the range of variations possible. To gain meaningful cohort analysis of these data requires advanced statistical methods outside the scope of this thesis.

Within this trial when administering the use of the quality of life and self-efficacy for chronic disease self-management measures the participants were expected to relate their answers to their COPD only. This is problematic for a number of reasons. Firstly because the participant's quality of life and ability to manage their chronic illness is impacted by all their conditions and one condition or response is not easily separated from the others. Secondly, as with their clinical condition, it is reasonable to anticipate that, for most participants, over a twelve month period there would be some degree of deterioration in their quality of life. Finally the participants have regular exposure to the same questionnaires over the period of the trial and many reported boredom with these questionnaires. They expressed a desire to complete them as quickly as possible and some could quote questions verbatim. This then leads us to question the accuracy of some of the results.

With a traditional approach to evaluating the effects of the introduction of a non-mandatory online patient diary it appears that the online patient diary has no positive effect upon patient health outcomes, particularly in relation to the development of self-efficacy for self-management of chronic illness.

Significantly, through using these aggregate quantitative measures there is no ability to determine the degree to which those individuals who adopted the online patient diary utilised the tool, or the degree to which they came to understand the complex relationships within the intervention related processes. The phase one analysis has not looked at the quantity of the data entered by participants either through the paper-based or online diaries[8]. This analysis was included within phase three in terms of the individual case studies and will be discussed further in section 8.5.

[8] This analysis is outside the scope of the current analysis and is being undertaken by the Pathways Home for Respiratory Illness Project research team.

Finally, quality of life for those suffering from a chronic illness is "a product of complex interactions between subjective health, disability and the social environment in which the individual lives" (Anderson & Bury, 1988, p. 249). Thus, it is inadequate to attempt to understand the impact of any intervention in the lives of people with chronic illness solely in terms of generic quality of life survey instrument measurements.

However, from the outset this research sought to delve into the experiences of participants to explore the impact of the intervention at an individual level. The next section provides an interpretation of the analyses contained in Chapters 6 and 7 and through this explores the impact of the online patient diary from a qualitative perspective.

8.5 Qualitative Impact of Online Patient Diary

This section engages in an in-depth interpretation of the findings from Chapters 6 and 7 in response to the first objective of the second research question. The research question is:

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO1 To qualitatively explore the impact of the online patient diary.

8.5.1 Influence of the Online Patient Diary

This section provides an interpretation of the data in relation to the impact of the online patient diary. This interpretation cannot and does not solely relate to the impact of the online patient diary as it is necessary to provide some interpretation of the impact of the paper based diary tool as well as the online patient diary.

From this research it has become evident that use of the symptom monitoring diary does not necessarily equate to positive gain for participants. Positive outcomes from using the symptom monitoring diary are possible, regardless of whether the diary is completed in paper form or online. However, within this research group a positive response to the diary was much more evident in those using the online patient diary than in those using the paper diary.

In chronic disease self-management programmes, symptom monitoring diaries are widely recommended and may be completed using either a device (e.g. blood sugar level monitoring in diabetes) or through the subjective interpretation of symptoms (e.g. breathlessness) as used in this project (Flinders Human Behaviour & Health Research Unit, 2004).

Regular recording of symptoms clarifies when, how much, and in what context the symptoms or changes occur. However, symptom monitoring in isolation is rarely an effective method of managing symptoms (Blanchard et al., 1990a; Blanchard et al., 1990b; Greene & Blanchard, 1994). Symptom monitoring has been found to increase an individual's self-management practices, such as their ability to undertake preventative actions (Clark, Evans, et al., 1994).

As an intervention, symptom monitoring diaries have been found to be most effective when used in conjunction with an individualised written action plan that indicates when and how to adjust treatments based upon symptom changes (Gibson et al., 1998). In this project the symptom monitoring diaries were used in conjunction with the mentoring intervention, including personal goal setting and action planning (see Section 2.5).

One of the core components of the intervention within the Pathways Home for Respiratory Illness project was the introduction of the symptom monitoring diary. As described in section 2.5.4 the participants initially used a paper based symptom monitoring diary to provide the opportunity for them to become comfortable with daily self-monitoring and reporting processes. They were then able to progress to using the online patient diary at their own pace.

Introduction of the online patient diary was only through a request from the participants. Participants were given information on the availability of the online patient diary during the initial recruitment stage. Only one of the participants in this research, Janice, expressed an interest in using the online patient diary at this stage. Once the participants reached the six week post enrolment point, the mentors initiated a conversation about the possible use of the online patient diary. In addition to this the research assistant discussed the use of online patient diaries with all participants at the three month data collection period.

The initial information about the online patient diaries, given at recruitment, was at a time when the participants were vulnerable due to their hospitalisation and many had difficulty understanding the information that was being given to them (see section 8.6.2). This information about the online patient diary appeared to have no obvious impact upon the uptake, except in the case where the participant already had a computer. "She wanted to use it from the start. She was really eager to do it and she had the computer" (Janice's Mentor).

The potential for the mentors to influence the uptake of online patient diary was most evident in the fact that they made judgements about their participant's capabilities and interest. These judgements influenced whether they discussed the possibility of using the online patient diaries with their participants. This is identified in the following quotes from two mentors "no, just because, you can picture a man like Albert, you know, age, stage, where he's at. No" (Albert's Mentor) and "if I did it was probably put aside fairly quickly and so it doesn't even ring in my mind that I did" (Gaye's Mentor).

In addition, if the participants had declined the use of the online patient diary the question was not raised again by the mentors. "I asked her in the beginning whether she was going to be a person who would be interested in having a computer and she just said no" (Francine's Mentor) This potentially resulted in participants who may have benefited through using the online patient diary not having access. This was also associated with the judgements made about participants; if the mentor or research assistant decided that the participant was capable of using the online patient diary they would offer multiple times. If they were deemed unable or unlikely to use the online patient diary by the mentor the possibility was not raised again.

The mentors had mixed levels of comfort and ability with technology. Only two of the mentors interviewed considered that they had good computer skills; neither of them had participants who used the online patient diary. There is little evidence to indicate

that the mentor's confidence with technology had any effect upon the participants' uptake of the online patient diaries but it may have been a reason why the mentors were not more persistent in initiating their use. The mentors were found to be more encouraging about the online patient diary when they had multiple participants, irrespective of whether they used the online patient diary. This appeared to be due to the ability to easily monitor multiple participants' symptoms but may also have been a result of the mentors having a better understanding of the trial processes through greater exposure.

Due to her role of visiting participants and administering the quarterly surveys the research assistant considered that she had only a limited understanding of the purpose of the symptom monitoring diary and the other aspects of the intervention. The research assistant did ask participants at each visit if they were using the online patient diary and if they would like to use it. At interview she could note the differences in the attitudes and understandings of the participants who actively engaged with the online patient diary. This knowledge also extended to comments about which of the other participants could have benefited from its use.

> [H]e would have been good with the computer he would have actually been one, had he had a phone on, who would have been. Yeah I reckon he would have managed that really well and it might have changed his whole slant on the thing as well (Harold's RA).

The research assistant was able to demonstrate a depth of knowledge about individual participants and had the ability to provide comparison across the whole group.

Analysis of the interviews provided evidence that, although the majority of participants interviewed continued to complete the diary, they were unsure about any benefit they had gained from the symptom monitoring. Only four participants reported any benefit from the symptom monitoring diaries. Significantly, all those who reported benefit were participants from the IT case group, although one of these participants, Beryl, rejected the online patient diary and reverted to using the paper diaries (see section 7.3). This participant's attempts to use the online patient diary were primarily aborted due to external factors involving her partner. She did state that "Yep if I'd knew what to do with it I'd have been quite happy and I'd have kept it" but her partner would not allow anyone from the project to return to the house to show her how to use the online patient diary after the initial visit and so she was unable to become comfortable with its use.

For those who chose not to use the online patient diary most appear to have had no doubts about their decision. They did have the opportunity to change their minds at any stage, but they did not express any desire for change or any regret at the interview. The exception to this was Harold who did not have access to a landline and so could not use the online patient diary. This participant considered that he would have been more involved and got more out of the project had he had access to the online patient diary. This was confirmed by both his mentor and the RA. However, he was provided with options to enable him to use the online patient diary, to have a landline installed or to complete the diary using his son's computer or an online community centre computer. For this participant there was no financial issue involved and the fact that he declined these options could indicate that his commitment to changing his health related behaviours was not high. This in itself may have been the result of the stage of his illness and his degree of understanding. This is evident from the following comments by his mentor.

> [T]his gentleman was non accepting initially of his disease ... because initially this man thought that he going to actually get better. And he was constantly saying to me that when I get better, when I get better (Harold's Mentor).

It is possible that the realisation of benefit from the online patient diary may in part be an artefact of the additional exposure to the project team that occurred through the process of installing the computer and teaching them how to use the online patient diary. This process may have provided them with an altered or extended understanding and appreciation of the way the intervention was designed to fit together.

During the installation process participants electing to use the online patient diary received three home visits and a number of telephone calls from a member of the project team. The cases included in this research were all visited by the same team member and a standard process, described in section 2.7.1, was used. Therefore, through the installation and training process additional understanding of processes and importance of linkages between these was imparted.

The participants' motivation to adopt the online patient diary may have had some impact upon how useful the participants found it. Two participants in the IT group did not find the online patient diary useful, although they did not find the paper based symptom diary useful either. They both said they adopted the online patient diary because they were asked if they wanted to. "I was asked to. And seeing as I had plenty of time up my sleeve I thought that I would have a go. Perhaps if I had been eighty percent fit I wouldn't have done it because I would have wanted to go outside" (Edward). Constance adopted the online patient diary because she was asked if she wanted to complete her diaries online and she thought it would be a good idea. But she had trouble "I'd get confused trying to get into the internet (chuckle) and sometimes it comes up and I've made a mistake somewhere and I can't work out where I've gone wrong".

Similarly all positive participant comments relating to the diary feedback were from the IT group. Two of the IT group did not find the feedback chart useful, but the remaining four did. The increased positive reception of the feedback may have been due to the rapid nature of the response as those in the non-IT group did not receive their feedback for at least 3 days after it was posted. Thus that data for the early part of the weekly diary could be up to ten days old before the feedback was received. Additionally, those reporting that the feedback was useful had also received the additional training associated with the computer introduction and this may have positively impacted upon their reactions.

Attempts were made during the trial to minimise the potential impact of the additional contact time with the IT group through the utilisation of a standard protocol for these visits. However, it appears that there was an effect for many of these participants. This may be a result of the graphical nature of the online demonstration and the way it was presented using simple language. This issue of understanding and language will be further explored in section 8.6.2.

All the mentors had access to the diary feedback online irrespective of the mode by which the participant entered their symptoms. Despite their initial reticence about using computers the mentors universally expressed their approval of the diary feedback as it was presented to them (see section 6.2.2.3 and Appendix 6). The triad

interview analysis did not demonstrate any evidence of the mentors having used the feedback sheets in consultation with the participants for education purposes or to reinforce behaviour change. This does not mean that this did not occur but if it did it was not considered within the context of the interviews.

Mentors utilised the diary feedback prior to their mentoring sessions as a mechanism for monitoring their participants' condition. They also used it during the mentoring sessions to trigger associations within their conversations and to aid the goal setting and action planning processes.

> When I got on the computer I'd have a look at it before I'd ring her. It just gave me some sort of idea of what colour she was talking about. And that's been good actually being able to get on there and do that (Francine's Mentor).

Interestingly some participants also used this for testing their mentors

> He used to say to me "you haven't been looking at the diary have you, or you would have seen what happens" (Edward's Mentor).

The mentors appeared to have given more attention to the diary and feedback in the cases that used the online patient diary as they commented that they "do them online now so and that really is useful because you can pick up from how they were yesterday rather than you know a week ago"(Lola's Mentor). They were generally most positive about those participants who used the online patient diary effectively, as was the research assistant. It was evident from the mentor and research assistant interviews that the proposed benefits of the total intervention, and the online patient diary specifically, were actualised in cases D, J and L. For example:

> She'd bring up diaries and she'd bring up mentor and she'd bring up everything to do with the project. She knew every angle of it. So yeah her conversation was a lot different (Janice's RA).

For those participants reporting benefits from the use of the online patient diary the specific benefits reported were related to improved knowledge and understanding about their individual disease responses. This included identification of triggers that caused a deterioration of their condition. For some this was limited to things such as identifying that increased social activity could lead to a rebound increase in their dyspnoea levels. Others identified a range of factors that impacted upon their condition such as the weather, frustration with self or others, anxiety or depression and the impact of medications.

Those participants who identified these linkages were able to initiate actions, or plan their activities to minimise or manage these effects. Actions included planning for activities and ensuring that they scheduled rest days when activity levels were increased, asking visitors to leave when stress levels were increasing and the early initiation of antibiotics to limit the extent of exacerbations.

The excerpt of diary entries for Janice (Table 8.1) demonstrates how well the online patient diary works for some of the participants. This participant found that through monitoring her symptoms she could see the relationships between her activity levels or other factors and her symptoms. This enabled her to have planned recovery days when she anticipated very active periods. She also determined patterns in her medication requirements and demonstrates an increased understanding of the linkages and interactions between the symptoms and treatments associated with her COPD and those of her other co-morbidities.

Table 8.1: Example of diary entries from Janice.

BREATHLESSNESS	COUGH	SPUTUM	FEEL	ACTIVITY	MEDICATION	DIARY COMMENTS
No Change from Normal	No Change from Normal	No Change from Normal	No Change from Normal	Slightly More	Moderately More	Quiet day.. Too cold out side...not a great change from yesterday with breathing...Still very tired.
No Change from Normal	No Change from Normal	No Change from Normal	Slightly Better	No Change from Normal	Moderately More	Better day... Friend in for lunch...Out on scooter...Felt better after my depressing day Sat...Breathing improved.
No Change from Normal	No Change from Normal	No Change from Normal	No Change from Normal	No Change from Normal	Moderately More	Visit to G.P.for review.. Weight down to 90kg so reduced fluid tabs back to 2 daily... Breathlessness eased..Weight fluctuation is due to deterioration in heart failure..
Slightly More	Slightly More	Slightly More	Slightly Worse	No Change from Normal	Moderately More	Attended PHysio but not overly physical...Quite breathless again today..Slight change in sputum and colour...Had blood test done for potasium levels and electrolite levels.
Moderately More	Moderately More	Moderately More	Slightly Worse	Less than normal	Moderately More	Having problems again today...Change of cough,sputum and breathlessness... Have increased fluid tablets again as directed by G.P...If no improvement, will start antibiotics as directed by my G.P. tomorrow...Quiet day resting once again.
Moderately More	Moderately More	Moderately More	Moderately Worse	Less than normal	Much More	Started Resprim Forte"today...Struggling again with shortness of breath... I seem to be going around in circles...Oh well
Much More	Much More	Much More	Much Worse	Less than normal	Much More	Not feeling very well...Hopefully Resprin" will do it's job soon...Very sleepy and lethargic once again...Slept all day..Hopefully I will be well enough to attend a Lung Net seminar tomorrow Sat...If sleeping and resting are pre requisites for good health I'm doing well"
Moderately More	Moderately More	Moderately More	Slightly Worse	Less than normal	Moderately More	Attended... Lung net seminar at Campbell Town...Very tired and breathless but decided to go anyway...Armed with puffers, oxygen and helpful friends survived the day...totally exhausted when I arrived home but well worth the risk taking the trip...No doubt
Moderately More	Moderately More	Moderately More	Moderately Worse	Less than normal	Much More	Very slow.... Bad breathing...Slept all afternoon with V.Pap machine...Things need to improve...

This is also confirmed by the mentor:

> When I ring her, well when I was ringing her, I was talking about what how about your, you know what was happening with the diary and um you know talk about yeah how good the feedback was yeah. That was really positive I think she's out of all the diaries that I've had and that's not many but I've looked at other people's too, her's was excellent too because she could see when she had her dips and when she had her good days and you could see why and she expressed it really well yeah. (Janice's Mentor)

Interestingly, all of the participants who reported benefits from the online patient diary expressed a desire to continue to use the tool after the completion of their participation. This was facilitated and at this stage these participants decreased the regularity of their entries but continued to enter their symptoms approximately once a week after they concluded the trial. This suggests that even for those who found benefit from symptom monitoring the frequency of monitoring needs to be considered.

A number of participants, typically those who reported benefit, described the fact that in response to the formal daily symptom monitoring they had developed an automatic symptom monitoring or "start-up scan". This entailed mentally running through their symptoms and general feeling of wellbeing upon waking. These participants found that they did not necessarily need to write down their symptoms in their diary every day. The majority of these participants did continue to use their online patient diaries throughout their period of participation.

Questions regarding the frequency of formal symptom monitoring either using paper or online patient diaries are raised. For participants to continue symptom monitoring daily for a period of twelve months was a considerable undertaking. Under usual circumstances these participants would not be regularly monitored at home. With the introduction of home-based eHealth applications for chronic disease management people with chronic illness and their carers are increasingly utilising monitoring tools where no monitoring previously occurred. There are many reasons given for this increasing home-based monitoring (Celler, Lovell, & Basilakis, 2003) but the result is an increased burden for both the people being monitored and for their clinicians.

Conceptually this trial aimed to enable participants to learn more about their symptom based responses to factors influencing their day to day health in an attempt to prevent or minimise acute exacerbations. However, as the intervention was understood by participants, delivered and evaluated it resulted in compliance with a continuous monitoring schedule rather than the anticipated outcome.

There were a number of common characteristics for those who successfully used and benefited from the online participant diary. These characteristics are not claimed to be definitive determinants of who will use and gain benefit from an ongoing online patient diary but they may provide a point from which such an investigation could occur. It appears that those females living alone, with a higher level of awareness about their illness, moderate to high levels of isolation due to their disease but with a close family and support network and severe COPD are more likely to benefit from the use of an online patient diary. The impact of each of these factors will be further elaborated upon in sections 8.6.3, 8.6.4 and 8.6.5.

So it is evident that the symptom monitoring diary in this trial had a mixed degree of acceptance despite its high level of use. The high level of use appears to have been more a result of compliance with the trial protocols than with any real or anticipated benefit; this is further discussed in section 8.6.2. The online patient diary was useful to a number of the participants who used it. Only one of the participants who did not find it useful continued completing the online patient diary throughout the full twelve months.

Through this research it has become evident that the online patient diary was of benefit for some participants who used it and was frequently more useful than the paper diary. However, this research has enabled us to look more broadly than simply

examining the effects of the online patient diary. It has demonstrated that there were additional influences that were related both directly and indirectly to the introduction of the computer and Internet into these participant's lives. The broader influences resulting from the introduction of the online patient diary on participant's experiences is discussed in section 8.6.

8.6 Broader Influences of the Online Patient Diary

This section engages in an in-depth interpretation of the findings from Chapters 6 and 7 in response to the first objective of the second research question:

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

RQ2: RO2 To explore the wider influence of the online patient diary on individual patients' experiences through an holistic examination of factors and their interactions revealed by both the clinical trial and qualitative data.

The section provides an interpretation and discussion of the core findings of the individual case studies developed through this research. Although, only three exemplars of the individual case studies were presented in Chapter 7, data relating to all twelve case studies will be drawn upon in this section. As previously described (section 4.6.3) the individual case studies incorporate data and analysis from Chapters 5 and 6 in relation to the individual cases.

From the analysis of the individual case studies it became apparent that the introduction of the online patient diaries had a much broader influence upon the participants than was evident through the first two analysis phases. These influences expanded to include the wider impact of the introduction of computers and the Internet into the participant's lives, the impact of changes in support networks from participation in the trial and the importance and impact of participation issues upon the participant's experiences of the trial.

This section is divided into five subsections. Each of these subsections provides an in-depth interpretation and discussion of the key areas of: impact of the computer, issues relating to participation, isolation, support and the degree of significance of the illness.

Each subsection has the following structure:

- a brief statement of the interpretation;
- discussion of relevant literature;
- key contextual information; and
- deeper interpretation and discussion.

8.6.1 Influence of Computer

Through the introduction of the online patient diary each of the participants and their households were necessarily provided with computers and Internet access. This introduction of technology had a profound influence on the participants' lives. All but

one of those who did decide to use the online patient diary reported positive changes in their lives that were attributed to the computer and or Internet.

In this research it is evident that the introduction of the computer has a wider impact than just providing an enhanced feedback mechanism for symptom monitoring. The benefits were more visible in the cases where the participants suffered from more severe disease and so experienced greater isolation. Through the introduction of the computers and the Internet participants experienced new interests, changes in methods of and ability to communicate, confidence levels and social standing.

The potential for positive psychosocial outcomes for older people has been reported in people who have a better than average education and have had exposure to other technologies (Clark & Zimmerman, 1990). However, there is less literature to describe the psychosocial effects of computer use in populations where there has been less interest in computers or with limited access to newer computer technology. Contradictory evidence from a number of studies (Ajzen, 1988; Czaja & Sharit, 1998; Danowski & Sacks, 1980; Jay & Willis, 1992; Menec & Chipperfield, 1997) suggests that for this group of elderly people willingness to use depends upon many variables, including health status and support.

As was evident from this research many elderly people demonstrate an initial anxiety about using computers (Whitcomb, 1990). However, this negativity decreases once they have gained some computer experience (Dyck & Smither, 1996). Interestingly studies have shown that people who are more confident with using computers are more independent, maintain social networks and as a result have a higher level of satisfaction with life (Karavidas, Lim, & Katsikas, 2005). However, it must be remembered that participants in this research are becoming increasingly ill, are less educated and have had low levels of exposure to technology.

In a recent publication on household use of information technology the Australian Bureau of Statistics (2007, p. 11) found that 73% of all Australian homes had computer access; 88% of homes with children under 15 years have access and 67% of homes without children under 15 have access. In Tasmania the proportion of homes with computer access was much lower at 66%, the lowest rate in Australia. The same report found that 67% of all Australian households had home Internet access and the number of homes without children under 15 and without Internet access was 43%. Once again Tasmania had the lowest rate of household Internet connections with only 56% (ABS, 2007, p. 13).

In the period 2005/06 the proportion of homes in Tasmania with computer access was 60% and with Internet access was 49% (ABS, 2007). This is significant as the installation of the computers and Internet access for the participants within this research all occurred during this time period. Thus it is possible to see that the use of computers, but more importantly the Internet, was not widespread within Tasmania and was particularly unusual within the COPD cohort. Thus the introduction of the computer and Internet had wider implications for these people.

Furthermore, 77% of Australians aged over 64 years did not use the Internet from any site compared with only 8% of people aged 15-17 years. Similarly, 58% of people in the lowest income quintile and 40% of people with Year 12 or below education did not access the Internet from any location (ABS, 2007, p. 21). The participants in this research were all older, with low incomes and most with education levels of year 12

or below. Thus it is not unusual that these participants should be slightly resistant to the thought of using a computer in the first instance.

Similar Internet use rates have been recorded in other countries. According to Lenhart et al. (2003) 42% of Americans don't use the Internet. Significantly there were also 24% of the population who had no direct or indirect access to the Internet. But perhaps more importantly at the time of the study there was a large growth in the number of previous Internet users who had dropped out. This trend to stop using the Internet has been noted also in Europe (Wyatt, Thomas, & Terranova, 2002).

So within the research participant group only one participant had her own computer but that was quite old and had no Internet access as she could not afford the monthly access costs. Two of the participants reported previous experience with using computers and a further one had unsuccessfully tried to learn to use a computer. The person with previous bad experiences chose to use the online patient diary after approximately 4 months of using the paper diaries. She had no difficulty learning to use the computer at all and required only two support visits. At interview this participant was a strong advocate for the use of both the online patient diary and the computer. It is probable that a number of factors combined to overcome her previous bad experiences. This may have been due to the fact that she could see personal value in learning to use a computer. In addition she was learning in a non-threatening environment, her own home, without other people to watch her. She had additional support from her son and grandson who lived a few blocks away and encouraged her to use the computer for other purposes. For this participant the process of installing the computer and learning to use it became a family affair with two grandsons helping to set up the computer desk and the computer.

For most of the participants who used the computer the installation process was an event. They took delight in planning where the computer would go and had other people present at the time of installation. The exception to this was Beryl, who subsequently stopped using the computer. Beryl's partner was not present at the first visit, when the online patient diary was demonstrated, and Beryl assisted in selecting a location for the computer and freely offered conversation about the possibilities it allowed and that she was going to attend a computer course. However, her partner was present at the installation and she was now very doubtful about her abilities to use the computer or about where it should be located. Thus the process and support during the introduction of the computer appears to be very important.

Only Janice had her own computer and any Internet experience. However, as she had not had Internet access for a year she was extremely enthusiastic about this and could not wait to get it running. Janice required only a quick demonstration of the online patient diary and the setting up of a shortcut to the site to commence using the online patient diary.

For the other participants who chose to use the online patient diary old computers and dial-up Internet access was provided. One on one home based computer training was provided. As most of the participants had limited or no experience with computers they needed to be taught from first principles; this included explanations of the various components and cords. The participants required varied amounts of practice using a mouse and their requirements to minimise the effects of arthritis and poor vision were each individually considered. The installation and training processes are described in section 2.7.2 and the user manual is provided in Appendix 8.

As they were running old computers with dial-up modems they experienced slow Internet connections. However, this suited most people and only one had any complaints about the speeds. It must be acknowledged that this process probably would have been easier for all concerned had the participants been provided with new computers and broadband Internet access. Critically, this would not have been a true life demonstration as the many of the older people in this cohort would only have access to older computers.

The use of dial-up modems provided another issue, the inability to use telephone when on the Internet. However, as the participants had no experience of other types of connections this was not a complaint from participants but was an accepted requirement. In fact Doreen had to physically unplug the phone and plug in the Internet cable each time she wanted to go online but she did not have any issue with this. Another participant, Lola, voluntarily unplugged the Internet cable after each use just to make sure that the phone was connected and operating.

A further issue identified by some participants, relating specifically to the computers, was the incompatibility with newer software. This was particularly true for computer games, which a number of participants bought for their grandchildren to use. This did have some effect whereby participants were limited in what they could use the computers and Internet for.

A small number of participants expressed their ongoing fear of damaging the computers. This was in spite of a great deal of explaining about the hardiness of these computers. In the case of Lola this was because she once changed the desktop preferences to white on white and so she thought she had damaged the computer. For Beryl the fear of damaging something was extreme and she would not allow anyone to touch the computer. This had a very negative impact not only on her computer use but also on her general confidence (see Section 7.3 for more details).

Outside these initial experiences, there were further influences upon the participants' lives from the presence and use of the computers. These had a wide psychosocial influence on the participants. The participants reported that the computer gave them a new interest and they enjoyed learning and using the various programmes. They acknowledged the fact that had they not been ill or isolated they would never have had, or made, the time or interest to learn to use a computer.

> It sort of takes my mind off things otherwise I sit here and start stressing out about being bored but if I get on there concentrate on these games well (Constance)

> And seeing as I had plenty of time up my sleeve I thought that I would have a go. It is as simple as that. Perhaps if I had been eighty percent fit I wouldn't have done it (Edward).

This new interest was initially associated with learning how to use the computer solely to enter the online patient diary but for many, once they were familiar with the process of connecting to the Internet and using a website, they rapidly found other uses. This opened up opportunities that they had not considered, particularly in terms of communicating with others. This communication was not solely about electronic communication but included new understanding and topics for discussion with their families. These participants enjoyed leaning new skills and discussing them with others. The mentors and research assistant commented upon the range of skills developed by the participants who successfully used the computers.

As well as creating a new interest, computer games have been linked with improved reading, comprehension, memory, attention span and hand-eye co-ordination. Studies such as (Whitcomb, 1990) have demonstrated that computer use in the elderly may slow the decline in these motor and cognitive abilities.

All participants reporting benefits from the introduction of the computer played computer games regularly. The games were primarily limited to the pre-installed card games as compatible software was difficult to source. However, where family had similar hardware, participants (particularly Constance) did use other games. The computer games were initially used as a strategy to assist with development of mouse skills but they tended to become part of daily life for many of the participants.

Once the computer was installed there was no limitation on its use and there was no monitoring of usage patterns. In the initial stages some participants simply followed the web portal manual and only used the computer for entry of the online patient diary. Others explored the greater possibilities that the computer and Internet offered.

All online participants were provided with email accounts and briefly shown how to use them. Only three of the participants interviewed subsequently used email and only two regularly. Janice was the most regular email user. She had previously had an email account but due to the inability to pay for her Internet connection she had not had access at home for twelve months prior to entering the trial. She utilised email frequently and particularly for communicating with her children and friends when they were away. Doreen also used her email account and through the Internet she made contact with a previously unknown relative in the USA and commenced email and telephone contact with her. In addition to this Doreen used an instant messaging application that her grandchildren installed.

After a relatively slow start the participants utilised the computers for a wide range of activities. It was not until close to the end of the trial that some participants, for example Edward, began to explore in more depth the possibilities of the computer. Beryl and Constance did not explore further, Beryl because she did not ever engage with the computer and Constance because she limited her interactions with the computer to playing games and reported having difficulty remembering how to use the dial-up Internet connection.

In contrast Janice and Doreen used their computers for a wide range of activities. Both were interested in genealogy and were using their computers both to search for information and to store and sort it. They also used word processing applications and undertook Internet searches for both general and health information. The health information sought was not specifically COPD related but often related to illnesses in family members. Not surprisingly, none of the participants reported using their computers for downloading or playing music, video or online games.

Janice also created and exchanged PowerPoint presentations with friends, used Photoshop to modify photos and sourced and exchanged knitting patterns. She set up a small business with one of her daughters and used the computer to create advertising materials for the business.

Both Edward and Lola were confident with their computer use and at the time of the interviews were beginning to explore further possibilities for use of the Internet. Both were interested in looking up information on the Internet and requested assistance

with learning to do this. Lola experienced some health set-backs and this decreased her use of the computer.

The power and importance of the Internet for educating people with chronic illness about their illness has been frequently reported (Bussey-Smith & Rossen, 2007; Välimäki, Nenonen, Koivunen, & Suhonen, 2007). However, for the participants in this research this function did not feature highly. This may have been in part attributable to the fact that the mentors were able to provide this information to them and they, as nurses, were a more trusted source of information. It may also have been a result of the low computing base from which they were coming. Because this was a trial based intervention the training on the computer was focussed on the use of the online patient diary and although the participants were shown the basics of using the Internet this was not the focus. If this intervention were to become mainstreamed it should extend to a broader frame for the education programme to encourage expanded IT use for health behaviours.

Changes in communication, outside electronic means, were also evident from the interviews. These changes included the increased ability to discuss computer issues or an enhanced understanding of games when the grandchildren visited. All the successful computer using participants reported conversations with family and/or friends which related to the computer and their abilities with it. Most also used their families as a port of call for support with their computers thus strengthening relationships.

There is evidence in most of the cases where the computer was used of a change in the participant's standing in relation to their family and friends. These changes are reflected in the increased visits from the children and grandchildren. This was reported by a number of participants where grandchildren would come and "help" them with their computer and stay overnight. All participants who reported this increase were very happy and discussed the way in which they could talk with their family and friends about their computers. This resulted in increased confidence with their computer use and for many an increased range of activities. These benefits were only achieved once the participant had a degree of comfort with using the computer.

Related with this was a sense of achievement and increased confidence in their personal abilities to learn. This sense of achievement was particularly evident in cases where there had previously been a fear of or inability to use computers.

The literature provides some evidence that interactive computer use with the right training conditions can increase self-esteem and reduce depression; this has been demonstrated through the Billipp (2001) study. There is some evidence that the participants who indicated benefit from the online patient diary did gain more confidence in their personal lives but there is no evidence to directly attribute this to the use of the computer, or indeed to their participation in the trial. These participants did, however, indicate gaining confidence in their abilities to learn new things through the significant achievement of learning how to use a computer. This was particularly evident from the case of Doreen who had previously unsuccessfully tried to learn to use a computer.

8.6.2 Participation Issues

This section explores the influence of two specific issues relating to participation that have been identified through the phase two analysis (section 6.2.2.3). These issues are the participants' understanding of the intervention and their reason for participation. Each of these impacted upon the participant's expectations, experiences and potentially upon the online patient diary uptake.

There is a complex relationship between the participants' understanding of the intervention and their reason for participation. Those who understood the intervention and identified that there was potential for personal gain were most likely to benefit from participation. All participants who identified personal benefit as their reason for participation had a good understanding of the intervention. In addition there is also no evidence of any participant who identified potential personal gain as a reason for participation having a negative outcome. In contrast those participants who reported no benefit all had a poor understanding of the intervention and identified altruism as their reason for participation.

8.6.2.1 Understanding of the Intervention

The difference in levels of understanding of the intervention had significant impact on the participants' expectations and experiences. This was influenced by the recruitment process and the language used during the recruitment.

Recruitment into the trial occurred in an acute hospital setting at the end of an acute exacerbation of their COPD. Thus participants were stressed, vulnerable and not necessarily receptive to understanding the trial that they were entering. Through the analysis conducted in chapters 6 and 7 it is evident that many of the participants had a poor understanding of the purpose of the trial and also of the intervention as a whole. They did understand the intervention in terms of individual processes but many did not connect these processes to form an understanding of the complete intervention. This was evident through the triad interviews where the mentors and research assistants confirmed the poor initial understanding of most of the participants.

In analysing the cases it became clear that the language used during the recruitment and the interactions with the recruitment team impacted on the understanding of the project. This is best described by Edward in the following quotes from his interview.

> That day that I spoke to <person recruiting>. Remember <person recruiting> and she was very hard to understand and to have to sit and talk to a doctor that's hard to understand at the best of times, she cannot give you the wording that you want to hear. If it had been from the likes of yourself, like an ordinary layman type explaining something to you, you would get it a lot clearer I'm sure of that.
>
> The other thing that I have found with her speaking to me is be it a professional person I had a lot of trouble understanding the words. They only know certain words and certain things in here. They don't know how the ordinary layman talks and puts that through.
>
> But that's what I find that professionals are very, and not all of them, but some of the people that with a sort of different accent. They can't express themselves the way that we have been taught to be expressed to us.....and that's one fault that I did find with it, that she couldn't tell me exactly what

was going on and she was in a hurry anyway and I had to wait for her to come and I was being discharged and I was ready to go home (Edward).

This demonstrates the importance and power of language for people entering into trials. This cohort of participants generally has a low level of education and were ill at the time of recruitment, so the language used to explain the trial should have been very simple to understand. This also calls into question why participants consent to be involved if they do not fully understand what they are consenting to. This is further explored in section 8.6.2.2.

Naturally it is to be expected that a participant, over the duration of the project, will have changes in their understanding. However, the degree of understanding elicited at the interviews, which were all conducted after a participation period of nine to twelve months, was low for more than half of the participants.

It is noticeable from the interview analysis that those who had a good understanding from the outset were both willing and able to engage in self-management activities. Additionally the participants who indicated a good understanding of the intervention who chose to use the online patient diary were the participants who gained the most benefit from their participation in the trial.

Of those demonstrating higher levels of understanding only one was not in the IT group. Interestingly this person was recruited by a different recruiter, who had identified that language was important to understanding in the recruitment phase. However, the effect of the additional explanations given during the training for use of the online patient diary was also not consistent, despite the training being standardised and delivered by the same person. From the available data it is not possible to delve deeper into the possible reasons behind these differences and this could be an area for further investigation in subsequent research.

The role of the mentors and research assistant in clarifying the participant's understanding of the intervention is unclear. Most of the mentors identified that there were gaps in the participants' understanding and attempted to fill these. However, there was no standard strategy for addressing this issue and as it was not identified until later in the trial, addressing it could confound the data. In addition each mentor and the research assistant appeared to have differing degrees of understanding of the intervention. Attempts were made to address this during the focus groups and through a revised training for mentors but this did not occur until May 2006 when these participants had already been involved in the trial for a period of time. Importantly, it must be recognised that three of the five participants with a good understanding of the project were recruited after April 2006 and so may have benefited from the retraining of the mentors.

8.6.2.2 Reason for Participation

From the interviews it was clearly evident that altruism was the strongest motive for participation in the trial. The participants all identified the researchers as those who would benefit from the research as well as hoping it would help people in the future. In addition many identified their respect for and indebtedness to the hospital staff and so associated their participation as a means of repayment.

It was rare for participants to identify personal benefit as either a reason for participation or as an anticipated outcome. This suggests that there is a disjuncture between the participants' understanding of the trial and their reasons for participation.

Green et al. (2000) examined incentives and barriers to enrolment in cancer clinical trials among African Americans using focus-group interviews. They identified that matters related to trust, relevance, and perceived benefit to the individual and the community were most important in the decision to enrol in a clinical trial. Additionally, Gross, Julion, and Fogg (2001) found that the degree to which the trial goals matched participants' goals impacted upon the attrition rate for trials.

The findings from this research confirm the importance of trust and perceived benefit to the community as being important in the decision to participate. However, the potential impact of the fact that many of these participants were used to complying with medical advice and that their specialists were part of the research team, cannot be discounted. The site of the trial recruitment was the only public tertiary hospital within the region. Three of the respiratory specialists were named on the introductory letter which gave validity to the research and encouraged trust but alternatively may have acted as an additional pressure to enrol. A number of participants commented that they thought that they had to enrol which leads to the interpretation that their participation may have been primarily the result of acquiescence to authority.

Five participants identified the possibility of personal benefit, in addition to benefit for future others, as being a factor in their decision to participate. These participants were those who experienced positive outcomes from their participation. Only one of these participants, Kerry, was not in the IT group.

Clearly there is a relationship between participants' understanding of the intervention and their reasons for participation. It is also evident that those who understood the intervention and identified that there was potential for personal gain from it were the ones who were most likely to report a positive outcome, regardless of whether they used the online patient diary or not. There was no evidence of any participants who identified personal benefit as their reason for participation having a poor understanding of the intervention. There is also no evidence of any participant who identified potential personal gain as a reason for participation having a negative outcome.

Through these considerations it is evident that it is important to take care with the language used in recruiting participants into a trial. Additionally, participants' levels of understanding and their reasons for participation should be explored as part of the data collection and analysis, for without these further investigations poor engagement may confound the results.

8.6.3 Isolation

Fraser, Kee and Minick (2006) identified that the psychosocial effects of COPD include feelings of social and emotional isolation, increased despondency and poor quality of life. Orbon et al. (2005) also describe these effects in people where their condition has impacted upon their ability to work. Psychosocial effects have also been linked with decreased adherence to treatment (Bosley, Corden, Rees, & Cochrane, 1996) and potentially with increased mortality, particularly for female sufferers (Almagro et al., 2002; Crockett, Cranston, Moss, & Alpers, 2002). Hence it is important to identify and relieve the psychosocial effects of COPD to achieve improved health outcomes and quality of life (Katz et al., 2005).

People with COPD also typically come from lower socioeconomic groups and have low levels of confidence in dealing with their health (Pauwels, Buist, Calverley, Jenkins, & Hurd, 2001; Prescott & Vestbo, 1999; Wong, Wong, & Chan, 2005). It is therefore important not to discount structural issues, such as low income and restricted access to resources, when conducting research within this cohort. These factors are important in understanding the care needs of such groups (Schoenberg & Drungle, 2001).

COPD is associated with anxiety and depression although it is unclear whether this is related to the stress of having COPD or whether anxiety and depression are part of the condition (Bailey, 2004; Dowson, Town, Frampton, & Mulder, 2004). In addition the symptoms of COPD such as disabling breathlessness, chronic cough and excess mucus production increase the sufferers' isolation (Williams, 1993). People with COPD are often further isolated because of the aetiology of their illness. COPD is frequently classified as a self-inflicted preventable illness (Dowson, Town, Frampton, & Mulder, 2004; Earnest, 2002) and there is evidence of this stigma even within medical publications (NHS, 2004). The introduction of and use of computers has been found to decrease the feeling of isolation in the elderly (Biordi, 2005; Pieper, 1999).

The combined effect of all the above factors is that people with COPD tend to become increasingly socially isolated as their illness progresses. For many elderly the visit to the doctor is not just about health issues it is about contact and an outing in a supportive environment.

Participation within a self-management intervention such as the Pathways Home for Respiratory Illness Project has the potential to either compound or ameliorate this isolation. Home monitoring can lead to decreased face-to-face contact and decreased visits to or from health carers. It can place a large burden of care upon the individual with COPD. In this study, through the provision of mentoring support and regular contact was maintained with the participants.

Through the provision of the online patient diary the potential for further isolation was possible. The participants no longer needed to go outside to post their paper diaries to the research office. However, through the provision of the computers the isolation levels of those participants who used them was decreased. They considered the computer to be company and a means of keeping in touch with the outside world. This was evident even in the case of Constance who used her computer almost exclusively for playing games. At interview she frequently commented that it kept her from becoming bored. All the participants who successfully used the computer made similar comments.

In addition the use of the computers for email and instant messaging allowed some of the participants to remain in close contact with friends and relatives when they did not feel able to venture out. This potential should be built into future research and would be enhanced by the use of an extended training scheme and the introduction of improved technologies.

However, it is important to balance the tensions between technological and human solutions to these problems. It is easy to become too enthusiastic about technology solutions to what are essentially human problems and it is important to view problems from different equally valid positions e.g. patient, carer, clinician, hospital administrator or technologist.

8.6.4 Support

This section explores the impact of support upon participants' experiences within the trial.

For all participants, irrespective of use of computer, support was found to be an important factor in how they dealt with their disease and therefore how they experienced the trial. The participants all preferred traditional methods of engaging with their support networks and did not explore the use of online forums or support groups. This may be because of the newness of the computers to them or because they had sufficient support through their current networks.

Three types of support were identified through the interviews: support from family and friends; formal support groups; and support from mentors. Each of these is discussed below.

8.6.4.1 Family and Friends

All of the participants in this research had some level of support from family members, friends, neighbours or carers. It is evident that some form of personal, one-to-one, support is very important to this group but they also require a degree of independence.

Family has great deal of impact upon the treatment and psychosocial aspects of chronic disease and COPD specifically (Barstow, 1974; Lamb, Borycki, & Marciniuk, 2002).

In relation to the participants in this trial family attitude had the potential to influence each participant's experience in either a positive or negative way. Family support and interest in the trial appears to have had a major effect on how people experienced the project. Those participants who lived alone, but had family who were supportive of the trial appeared more receptive to using the online patient diary and less negative about using the symptom monitoring diary.

Interestingly those who used the online patient diary and gained benefit either from the diary or just from using the computer were primarily people who lived alone but had close contact and support from with family members. Those who either did not have good family support or lived with their partners had different experiences. For some participants family support was the reason they commenced the trial and it also influenced their decision to continue with the trial. This was particularly evident in the cases of Francine and Ivan. Interestingly, those participants who had positive experiences without the online diary were women married to invalid partners for whom they were primary carers. This also links back to the relevance of the intervention or reason for participation (see sections 8.6.2.1 and 8.6.2.2.

In the case of one participant, Beryl, there was overt conflict in the home both in regard to her involvement in the project and in the introduction of the computer and online patient diary to the home. It would appear from the case study that this conflict went deeper and that Beryl was unsupported in many aspects of her life. The complex relationships here obviously impacted upon Beryl's ability to learn to use the computer but failed to impact upon her ability to make positive gains from the intervention as a whole.

8.6.4.2 Support group

Support groups have a specific role in providing support for people suffering from COPD. Many of the participants in this research were unaware of the existence of COPD specific support groups. Those who were members of support groups found they gained significant social and emotional support as well as providing a forum for exchanging information about their disease. There is evidence that support group membership contributed to improving the experiences of members engaged in the trial.

Two of the participants in this group, Janice and Lola, attended regular cardio-pulmonary physiotherapy classes. They found great support from attending these classes and from spending time with other COPD sufferers in these classes. Interestingly they assessed other members of the class, including each other, as having significantly worse illness than they do themselves.

Those who were members of support groups did better than those who were not members. They did not join any online support groups and these were not provided through the project. Maintaining ongoing contact with their existing support groups was found to be useful for these participants as it provided another source of information, psychological and social support.

There is no evidence that this group would have used or necessarily benefited from the provision of an online support network. However, given the degree to which those who chose to use computers utilised them for other purposes it may have been useful to the participants to have had access to online support networks.

Interestingly, of the participants who did not attend support groups only two indicated positive outcomes from the trial and both lived with their partners and continued working for at least six months of their participation. In these cases it may be that the regular attendance at work provided them with an informal support network.

8.6.4.3 Mentor

The mentors were seen as a major source of social contact by most participants. The majority of the participants did not fully understand the role of the mentors within the intervention and some participants had unrealistic expectations of the role of the mentor or would make requests that did not fit within the mentoring role. Most of the participants expected the mentors to maintain the traditional community health nurse role of teaching and telling. The mentors also found it difficult to work outside this model of care (Robinson et al., 2008). Both the participants and the mentors expressed a preference for face-to-face contact, rather than the telephone contact.

A number of the participants came to rely upon the mentors for a chat. They would discuss their lives in great depth and considered that having the mentors call them and keep an eye on them was the best part of the intervention: it made them feel safe. For these people the end of the trial was something to fear as they were going to lose this contact.

8.6.5 Significance of Illness

For many people with COPD it is not considered their most significant illness or disability. This is often noticeable at the less severe stages of the illness when the person has no significant limitations cause by their illness, for example Albert, or

when the severity of co-morbidities or other illnesses overtake the immediacy of their COPD, for example Janice. People with chronic illness tend to adjust their behaviour or norms accordingly to accommodate their disability into normal life (Deimling et al., 2006; Sharpe & Curran, 2006).

This section is divided into three subsections which provide different perspectives on how the significance of their illness influenced participant's experiences within the trial.

8.6.5.1 Perceptions or knowledge of illness

Disease knowledge is an important factor for eliciting behaviour change (Hopp, Lee, & Hills, 1989). However, within the trial there was no formal investigation of the participants' disease knowledge or understanding. It has become evident through this research that the participants' knowledge and understanding of the disease processes and trajectory have a large impact on how they engaged with the intervention. It is also evident that those with the greatest knowledge are those further along the trajectory of illness and that they are more able to engage with a self-management programme. This implies that for this group disease knowledge was gained as a response to requirements, not when they were diagnosed with the disease. The timing and location of delivering COPD education is critical for facilitating understanding and retention of information (Nault, Dagenais, Perreault, & Borycki, 2002).

This is evident in all interviews and warrants investigation. The participants who are earlier in the trajectory of their disease do not engage as well with the intervention as those who have been diagnosed for a longer period of time. It appears that they don't take their disease seriously until they have had a few acute exacerbations and often are not diagnosed until then. The problem is that with each acute exacerbation they lose a bit more lung capacity. If they don't take their disease seriously they are in danger of a more rapid deterioration. Examples are Albert and Harold.

From this group it appears that females take their health issues more seriously and have a greater understanding of their disease at an earlier stage as is evident from Kerry who had not been diagnosed with COPD for long but had actively sought information about her disease, particularly through her mentor. The male participants sought less information about their illness and this appeared to impact negatively upon their participation. There was evidence that the male participants assumed that if information was important then their clinicians would provide them with it.

Many of the participants, but particularly the male participants, appeared to have little knowledge about the trajectory of their illness and so did not identify it as a major problem. This had major implications for the trial intervention as without this understanding it was difficult for them to identify the significance of their symptoms and the impact of changes in these symptoms.

8.6.5.2 Stage or severity of illness

The stage or severity of illness appears to be of great importance within this research. It evidently had an impact upon the participants' ability to engage with the intervention. Stage or severity of illness appears to have been a trigger for action, and was also linked to knowledge and understanding of the disease. The female participants who had more severe illness either in terms of symptoms or respiratory function were those who engaged best with the intervention and who reported

improved outcomes. It would appear that within this group of people with COPD there is a link between the stage or severity of illness, disease knowledge and understanding, and the willingness or ability to engage in self-management activities. This may be because their symptoms and disease processes are impacting more upon their lives and they are compelled to act.

8.6.5.3 Impact/influence of co-morbidities

Within the trial the symptom monitoring and management of COPD was given primacy. The participants were therefore required to consider their COPD in isolation from their other conditions, even when it was other conditions that were of greater impact.

The majority of the participants in this research group suffered from a number of co-morbidities. For some the day-to-day impact of the co-morbidities, for example arthritis, was greater than the impact of their COPD. In addition to this the surveys and symptom monitoring required that they isolate their COPD from their whole of health experiences.

The types of co-morbidities had considerable impact upon the way in which people experienced the intervention. Two participants also suffered from Type II diabetes and were used to regular monitoring and self-managing the effects of the diabetes. They both commented that diabetes is easier to regularly monitor than COPD and that with diabetes they had better guidelines for managing and received regular feedback from their clinicians.

Those participants with more complex care requirements were generally more informed about their COPD and more engaged with the trial. However, whether this was an effect of the trial or of necessity for their overall health status is not clear from this research.

The next section will provide reflections upon the impact of the online patient diary as discussed in sections 8.5 and 8.6.

8.7 Reflections on the Impact of the Online Patient Diary

It was apparent from the interviews that most participants did not understand the intervention and so had difficulty understanding the relationships between the various processes. There is also the possibility that through their lack of understanding at the outset they signed up to a trial that was simply irrelevant to their lives. Whatever the reason the impact of the recruitment process and the language used in explaining the intervention on the outcomes of this research was significant.

Participants who voiced positive outcomes from participation in the trial fell in to two groups:

1. Previously active and involved women living alone with increasing disability which was progressively impacting upon their ability to continue with an active lifestyle. These participants all used the online patient diary and recognised benefits from its use.
2. Married women with heavily dependent spouses. These participants felt compelled to look after their own health to ensure that their spouse was looked after. Neither of these participants used the online patient diary, although one did attempt to do so.

Through this research it has become evident that the online patient diary was of benefit for some participants who used it and was more useful than the paper diary. However, this research has enabled us to look more broadly than simply examining the effects of the online patient diary. It has demonstrated that there were additional influences that were related both directly and indirectly to the introduction of the computer and Internet into these participant's lives, for example a heightened sense of achievement, decreased isolation and increased social standing.

A complex relationship has been revealed between project understanding, reason for participation and the stage of their illness that influences the decision to utilise the online patient diary. When these factors align there are indications that they can lead to improved symptom understanding and changes in self-management behaviour. However, these changes in symptom understanding and self-management behaviour are not necessarily reflected in easily measured outcomes

From this research it is evident that there was a mixed degree of acceptance of the symptom monitoring diary despite its high level of use. The high level of use appears to be attributable more to the participants' degree of compliance with the trial protocols than with any real or anticipated benefit. The online patient diary was useful to a number of the participants who used it. Only one of the participants who did not find it useful continued completing the online patient diary throughout the full twelve months.

Through this trial COPD has been viewed as the participants' primary concern but for many patients other health issues impact as well and often these have primacy, if only temporarily. Their priorities and how they deal with their COPD cannot necessarily be differentiated from their other conditions. Through attempting to force a distinction the trial may have introduced confusion for them and possibly even made them more conscious of their problems.

8.8 Conclusions

Through undertaking an evaluation of the clinical trial data it has become evident that the intervention has a positive effect on participants in terms of the self-efficacy for self-management and quality of life indicators. However, this effect appears to be diluted when the online patient diary is introduced. Through this analysis a number of issues have been revealed that may be relevant when employing descriptive statistics to evaluate a chronic disease self-management intervention. These include:

- The possibility that clinical outcome measures provide little relevant information at cohort levels although provide valuable information about individuals;
- Giving primacy to one condition, the condition under investigation, over other co-morbidities may lead to confusion on the part of participants; and
- This primacy may not reflect the participant's prioritisation of the condition.

The limitations of analysing these trial data at cohort level only have been demonstrated. Through this research the importance of delving deeper into the data and using multiple data types and sources has provided rich insights into the limitations of the clinical controlled trial data and the complexity of evaluation of it.

Although only a small number of participants found the symptom monitoring diary useful there was a high level of usage, which can only be accounted for through compliance with the trial protocols. Many participants did not use the diary when they were ill or in hospital. This indicates that they will comply with trial protocols when they are well but if there is not perceived benefit, or if they are already receiving treatment they do not continue to monitor their symptoms. This may be a result of them handing over responsibility to their doctor or it may simply be that they are too ill to be concerned.

This study has revealed a very complex narrative about the adoption and subsequent use of the online patient diary, which raises questions about simplistic accounts of the benefits of IT for patients within CDSM. The research has revealed that for meaningful evaluation of the impact of trials involving patients and technology it is necessary to be truly patient-centred and not disease centred. In this research a strict reading of the quantitative results highlights the following:

- Participants within the intervention group gained greater benefits in all self-efficacy for self-management and quality of life measures than the control group.
- Within the intervention group, those participants who did not use the online patient diary (all non-IT users) gained greater benefits in all self-efficacy for self-management and quality of life measures than those who used the online patient diary (all IT users). This would lead to the obvious conclusion that greater benefits ensue from the intervention without the online patient diary and so the IT intervention should be removed.

However, through the qualitative analysis and detailed exploration of the inter-relationships across all available data this research has revealed that:

- Factors such as a participant's understanding of the project processes and their reason for participation, along with disease knowledge and severity of illness all directly impact on decisions to adopt and to use and the ability to benefit from the online patient diary.
- The degree of isolation and social support, particularly family support, are very important in the decision to adopt and continue to use the online patient diary.
- Participants who did not adopt the online patient diary were less likely to gain benefit for the symptom monitoring diary. Their primary gain was from the increased contact through the mentoring process.
- Discontinued use of the online patient diary does not equate to decreased benefits from the symptom monitoring diary. The additional exposure to the project team through the training for online patient diary use may have positive effects through improved understanding of the role of the symptom monitoring.

In terms of the quantitative trial measures it is important to recognise that this research has provided only a limited descriptive statistical analysis and interpretation. A rigorous inferential statistical analysis is being undertaken by members of the

project team and this will ensure measures and results have not been misinterpreted, or inappropriate criteria used.

Significantly, the impact of introduction of the online patient diary is not restricted to the online patient diary or to the outcomes of the trial. The impact of the computer has been large and with better technology and longer training it could be greater. The impact of the introduction of the computer included:

- Decreased isolation
- Increased social standing with family and peers
- Sense of personal achievement

The participant's eligibility in trials is voluntary but determined by exclusion criteria. These criteria tend to be related directly to the disease of interest. These criteria frequently provide little or no indication of an individual's disease knowledge, their reasons for voluntarily participation or their understanding of the purpose of the trial.

From this study it has become evident that there is a complex relationship between *REASON FOR PARTICIPATION* and *PROJECT UNDERSTANDING*. This relationship appears to be further compounded by a participant's knowledge of their disease.

These complex relationships are particularly evident in the trial because of the closeness of the relationships within the community. Where participants know that their physician and local hospital are involved in the trial they therefore want to help. There is absolutely no evidence of collusion or coercion, but for some participants this is seen as a way of giving back to those who have provided them with medical care. These individuals however appear never to attain an understanding the full purpose of the trial. As a consequence, they remain unable to engage properly and tend to treat individual elements of the trial as discrete unconnected activities. Significantly, this disconnect, evident from this research, also appears not to prevent these individuals from scoring highly in individual measures used in the trial. These high scores offer the potential to be misinterpreted as signifiers of engagement, understanding and success.

Amongst participants who do achieve project understanding there is also a degree of altruism involved in their reason for participation. However, because of their level of disease knowledge they recognise the connectedness of elements in the trial and the potential to acquire benefit. Interestingly, amongst these participants there does not appear to be evidence within the trial measures of any marked positive difference from those individuals described above. Significantly however, the qualitative analysis shows many of these participants achieving outcomes that should be considered as indicators of success by the trial and are perceived to be positive by the participants themselves. In particular, the triad interviews revealed that participants with improved self-management skills illustrated by the use of their diary feedback in planning and predicting their daily activities also used the diaries to initiate treatment based upon their recognition of patterns of behaviour that had previously occurred. Critically, however these participants actually achieved lower self-efficacy for self-management scores than participants who had a poor understanding of the intervention.

Through acquiring a more in-depth and realistic understanding of their disease and its impact on their lives these participants become more honest and self-aware about their limitations, leading to a more dramatic tail-off in their self-efficacy scores over the lifetime of the trial. This clearly suggests the need for a more sophisticated reading of self-efficacy scores and their relationships to the participants' real experience, disease knowledge, project knowledge and reasons for trial participation.

Conventionally, it is anticipated that the learning burden associated with an intervention will initially have an impact on the results. Therefore it might be expected that the addition of the online patient diary and the associated technologies would provide an additional burden and that a subsequent difference between the IT cases and non-IT cases would be revealed. Indeed using HADS and self-efficacy in the periods immediately after adoption of the online patient diary there are identifiable differences.

However, in this research it appears that these measures continue to indicate differences and even become greater towards the end of the trial. This opens up a discussion into factors impacting on these differences. It seems difficult to attribute this continuing divergence between the IT cases and Non-IT cases to learning burden particularly as the triad interviews reveal that participants find the IT fun, easy to use and simple to learn. An alternative explanation is required.

Looking at the decrease in self-efficacy for self-management it appears to be the result of those participants who adopted the online patient diary learning more about their disease and symptoms (i.e. it becomes evident that the disease process is complex and that the inter-relationships between their disease process and life are difficult to manage). For the non-IT cases, as discussed above, their higher self-efficacy for self-management scores actually reflect their primary action when noticing a disease change as being a visit to the doctor. This action may or may not be appropriate or meaningful and it is rarely evidence of genuine self-efficacy for self-management rather a 'knee-jerk' reaction as a result of their pre-existing perceptions and experiences of being a patient firmly located in within the medical model of having medicine done to them rather than being an active participant in their care and decision making processes.

It appears that what is recorded as greater self-efficacy for self-management turns out on closer inspection to be actually a realisation of the need for medical care and thus a greater dependency on interactions with health professionals. This is not adequately measured, and remains hidden from view within these trials. Most significantly, this research indicates a need for a more sophisticated understanding of results as presented in this research.

More broadly, the above discussion points to a number of fundamental questions about symptom monitoring in the community. When is it a good idea to monitor people who have previously not been monitored? Why are we doing it? Who benefits?

Within and beyond this trial there appear to be unconsidered implications for clinicians through the introduction of widespread symptom monitoring in the home. With this increasing pool of patient information comes the imperative for clinicians to review and react to this information in their decision-making, both during consultations and at times outside the consultation. This can lead to information overload and beyond this there are medico-legal implications for its analysis and actions occurring, or not occurring, as a result of this increased availability of patient

monitoring. This also links into consideration about workforce burden at a time of staff and other resource shortages in healthcare.

It also raises questions about the appropriateness of giving primacy of one disease over another when trying to monitor, for example; asking patients to undertake symptom monitoring in terms of only their COPD. This is not an holistic patient-centred approach but it is the prevailing one. This does potentially increase an individual's task burden and can lead to additional issues/challenges including increased anxiety and depression and the need for more consultations for reassurance.

8.9 Reflections

This chapter has provided an interpretation and discussion of the data from the analyses provided in Chapters 5, 6 and 7. This interpretation and discussion has identified that when using quantitative analysis methods alone the online patient diary appears to dilute the overall efficacy of the intervention. However, it has also provided strong evidence that when this investigation is expanded to include qualitative research methods different results and foci emerge.

The next chapter, the final chapter, outlines the conclusions of this research. It provides a review of the major findings along with an outline for future work in this emergent research area.

Chapter 9 Conclusions & Future Work

> To cope with escalating complexity in health care we must abandon linear models, accept unpredictability, respect (and utilise) autonomy and creativity, and respond flexibly to emerging patterns and opportunities (Plsek & Greenhalgh, 2001, p. 628)

9.1 Introduction

This is the final chapter. It provides a synthesis of the key findings and discusses the contributions this thesis makes to the broader health informatics discipline. This chapter also considers the implications of the findings of this thesis for researchers within the health informatics community conducting and evaluating patient-focused eHealth research projects. This chapter also includes a section on the limitations of this study and suggested areas of future work.

This thesis has addressed the following two research questions, each with two research objectives:

RQ1 What impact does a mentored self-management intervention have on health outcomes for people with chronic obstructive pulmonary disease?

- RQ1: RO1 To describe the impact of the overall intervention on health outcomes; and
- RQ1: RO2 To explore the impact of the online patient diary on health outcomes within the intervention.

RQ2 What impact does the introduction of an online patient diary have on individual participants' experience of a mentored self-management intervention?

- RQ2: RO1 To qualitatively explore the impact of the online patient diary; and
- RQ2: RO2 To explore the wider influence of the online patient diary on individual patients' experiences through an holistic examination of factors and their interactions revealed by both the clinical trial and qualitative data.

9.2 Synthesis of Findings

This section provides a synthesis of the findings described in detail in Chapter 8. The key findings are structured in terms of: impacts of the online patient diary in general and upon participants specifically; factors which influenced the uptake and use of the online patient diary; and project conceptualisation or implementation factors.

The key findings of this thesis are:

Firstly, that conventional clinical and quality of life measures when used to provide an indication of the efficacy of an online patient diary provide the result that the use of the online patient diary decreases the efficacy of the intervention.

Secondly, that qualitative techniques used on the same intervention group reveal that a number of participants using the online patient diary increased their understanding of

their symptoms and the effects of external factors and change upon their health and ability to cope.

These two apparently conflicting results highlight that the online patient diary and its use impacted positively on factors that were not measured within the clinical trial and were only evident through gaining a deeper understanding of the participants and their lives.

Significantly, a number of the benefits that are attributable to the introduction and use of the online patient diary by patients were not directly related to the tool per se but were related to changes in the participants':

- ability to communicate more widely and easily;
- social status within their families and social groups;
- perceived levels of isolation; and
- confidence about themselves and their capabilities.

In relation to the clinical condition of participants the study revealed that those with more significant disease symptoms were more likely to use the online patient diary and at interview reported greater benefits from it both in terms of their disease awareness and of social benefits.

The project team's attitude towards the abilities of the participants had an impact upon the actual level of understanding, uptake and use of the online patient diary. Once participants were comfortable with using the online patient diary they expanded their use of the computers to a range of purposes.

There were two specific internal project factors identified that inhibited the success for this project both in general and in terms of the specifically. These were:

- the language used by the research team to explain the intervention, initially and throughout the trial, resulted in participants having a poor understanding of the purpose of the intervention; and
- the participants' reasons for becoming involved in the project were confused because of their poor understanding of the purpose of the intervention. Many actually became involved for altruistic reasons rather than in anticipation of helping themselves; this appeared to subsequently 'colour' their participation, experiences and results from the intervention.

The project team's conceptualisation of the online patient diary and its role within the intervention imposed significant constraints on the ability to utilise patient-centred design principles when developing the online patient diary. This emphasises the tension between clinical and design imperatives within health informatics.

9.3 Research Contributions

This section reviews the contributions which this thesis makes to the study of interventions involving IT, patients and chronic disease. The research contributions can be presented at three levels: the theoretical, the methodological and the substantive level.

More broadly, the research highlights some implications for practice both to health informatics academia and to other practitioners looking to establish and working within the health informatics domain. It has also provided an opportunity to generate insights of relevance to the health informatics discipline.

9.3.1 Theoretical Level

Researchers in eHealth must grapple directly with a range of competing paradigms that have different ontologies, epistemologies and philosophies, and therefore different methods, data, and value judgements. Into this mix comes technology, and, when we deal with chronic diseases, patients and their families. This research emphasises the need to reassess the way researchers and health care providers conceptualise the 'patient', because increasingly they are directly involved within research projects and particularly in the use of technology for self-monitoring or self-management. Through this project the concept of self-monitoring for self-management has been taken to a more advanced level, with participants being provided with the means to observe and interpret their symptoms over time to enable them to gain an understanding of factors that impact upon their individual condition. This new conceptualisation of the patient as an active and knowledgeable participant in their own care needs to be incorporated into health care models, and particularly into eHealth developments which will support a sustainable model of care for people living with chronic diseases in the community.

Thus this research provides evidence that the development of IT tools for patients to use in self-monitoring and self-management requires an understanding of the people, their families and the communities involved, along with the social, psychological and economic factors that impact upon these people's abilities to embrace these changes the work should not focus solely upon the clinical factors of their disease.

Much of current eHealth theory is based upon measuring the impact of ICTs within the constraints of an organisation or organisational type, and while these models may work within these homogeneous environments they are ill suited to evaluation of the impact of non-mandatory systems in individual homes. These theories and methods have been appropriate until now, as there has been an emphasis within health informatics upon the introduction of information systems into institutional care. As the focus, both in terms of health care and health informatics, moves towards care outside institutional boundaries new challenges emerge. There can no longer be mandatory use of systems, people will adopt and use systems in ways that suit themselves and their lifestyles and not necessarily as the system designers anticipate. This leads to a requirement to change the ways in which we evaluate the impacts and benefits of systems. This research has provided insights into some of the factors that have led participants with chronic illness to use a non mandatory online patient diary but also, and no less importantly, it has provided some insights into why people choose not to use these tools. When evaluating the efficacy or impact of IT tools upon people living in their own homes it is essential to consider the social setting, disease type, the ways in which the IT tools are utilised and also why they are not utilised and who by. More information and insight can often be gained through examining who did not adopt and why not, rather than merely looking at the successful adopters of technology.

Within this research theoretical conceptual models on trials are challenged through the desire to explore the deeper impacts and the range of impacts. This analysis has demonstrated that combining conventional trial models and qualitative models within a subjective ontology, and using an interpretive epistemology, can provide a rich model for exploring impacts at cohort, group and individual levels. By expanding conceptual models of clinical controlled trials in this way it is possible to enhance the breadth of understanding of the impacts of interventions. Thus some of the current limitations of clinical trials can begin to be addressed.

Theoretical conceptual models of patients as passive recipients of care who will conform to the expectations of doctors, act in predictable ways and share a common value structure are outdated and fail to address the current and future roles of patients with chronic illnesses. However, these models continue to be used within clinical trial environments and hence the results fail to explore or address external patient factors. This thesis has demonstrated that the conceptualisation of patients in this manner fails to allow for the exploration of other factors which interplay within a patient's life and their experiences and expectations within a clinical controlled trial.

9.3.2 Methodological Level

Methodologically, this thesis has utilised both quantitative and qualitative data across cohorts, groups and individuals to build an expansive view of participants' experiences and outcomes within a controlled trial. By combining the analysis of the clinical controlled trial data with interview data this research has applied a novel method which provides the researcher with the ability to gain insights at multiple levels of abstraction and provide access to insights that would not otherwise be possible.

This thesis provides insights into methods by which the impact of IT tools can be explored in the heterogeneous environment in which people live.

Finally this thesis has provided an exploration of methods through which the findings from clinical controlled trials can be re-personalised and so provide a means by which "outlier" activities can be explored or explained.

9.3.3 Substantive Level

At a substantive level this research has provided insights within the confines of a clinical controlled trial of an intervention to improve participants' self-efficacy for self-management of their chronic obstructive pulmonary disease. These insights are discussed below:

This thesis has provided evidence which challenges the assumption that the impact of an online patient diary can be separated from other life and/or project influences and hence measured easily. The measurement of the impact of a non-mandatory online patient diary is in itself a complex undertaking. However, it is difficult to understand the impact that such a tool can have within the confines of a clinical controlled trial of an intervention to improve participants' self-efficacy for self-management of their COPD. The research has demonstrated that there is no standard response to the introduction of such a tool, and for researchers undertaking similar types of research it is essential to use a variety of data collection techniques in order to explore the phenomenon in greater depth.

This research has provided insights that challenge the assumptions that an online patient diary for self-monitoring will be used or that through self-monitoring people will axiomatically learn to understand and manage their illnesses. These assumptions are problematic as they assume that people all have similar responses to the experience of having a chronic illness and that this response results from a desire to understand their illness and become actively involved in its management. There is also an assumption that people are interested in and able to learn how to utilise IT tools to monitor their condition. This research has demonstrated that there is a wide range of responses to this type of intervention and it is essential to provide a range of tools to participants and allow for the possibility that more than one tool may be used dependent upon personal circumstances and preferences. It is also important for health informatics researchers to remember that paper is also a data collection tool and sometimes a solution without an IT tool is a valid outcome.

This research has illuminated the difficulties that will be experienced by health informaticians when implementing eHealth solutions into peoples' homes and in the community. The research has demonstrated the limited abilities and experiences that are evident in many members of the community who suffer from COPD. These people do not have access to, nor experience with computers. Significant time, money and effort are required to enable similar groups to gain access to any potential benefits from the use of eHealth applications. It is essential for the future of community health informatics and for the sustainability of health care that significant investment is made into providing these resources for all and ensuring now that we do not establish an eHealth divide.

When evaluating the impact of an IT tool it is relatively easy to evaluate it in terms of the prescribed activities but the practical impacts are less obvious although frequently of more importance at the individual level. It is easy to measure the number of times a person has completed a diary or looked at the feedback sheet or even utilised what they have seen to alter their health management. However, the evaluation of the effects or impact of less tangible or indirect changes is more difficult. This research has highlighted the interconnectedness of the relationships between the participant's social, economic psychological and health related factors and their ability or desire to adopt and learn to use a self-monitoring tool, be it technology based or not.

This research has highlighted a number of questions that should be considered when commencing or evaluating the impact of a clinical controlled trial. These questions include:

- What motivates participants to sign-up for the trial?
- What is their level of understanding of the trial purpose, processes and outcomes?
- How does the participant's relationship with their health care provider(s) impact on their decision to enrol? and
- What is the potential impact of the answers to each of these questions upon each other and the participants?

This research has demonstrated that for this group of people with COPD it is important that the trial is structured in a manner that does not lock them into the paradigm of the research team and fails to make use of and acknowledge their own life experiences, attitudes, thoughts and concerns. The research design must be

flexible enough to enable the individual's pre-developed coping mechanisms to be incorporated into the activities and not be underestimated or undermined.

Within research trials it is advisable to utilise validated and standardised evaluation instruments. The trial within which this research was located used instruments of this type. However, there are limitations to these instruments. In particular the fact that they are generalisable means a loss of the ability to be individualised. When designing a trial it is difficult to conceptualise the possible range of responses of participants to any single intervention. This difficulty is compounded when the intervention is not able to be isolated from other external factors or influences, for example social settings. Thus the research has demonstrated the need to not only question the strength of these measures but also to provide alternative methods through which to explore the impacts of interventions.

Finally and possibly most importantly this research has highlighted to the researcher the questions of the morality, difficulty and ethics of withdrawing such an intervention at the conclusion of a trial. Despite the fact that participants enter into such trials understanding that the intervention will be withdrawn after a certain point it is not possible for them or the researcher to fully understand the impact of this withdrawal. For particularly vulnerable participant, as many of these were, it is possible for a dependence relationship to form both with the mentor and with the online patient diary. So it is important to provide a withdrawal plan and a follow-up evaluation to ensure that the participants are not harmed by the withdrawal of the intervention.

9.4 Implications for Practice

This research has provided evidence of the importance for the health informatics community of beginning to think about patients/citizens and their personal environments as the next challenge for the health informatics discipline. This means that change needs to be driven by and for people living in their own homes and communities and not driven by technology and/or health care providers. The technology and/or its use do not have to be sophisticated to have a major impact upon an individual's health. Any solution provided should be able to be accessed and used by any member of the target community not just those with the personal resources to gain access. Working to this ethical stance provides a challenge for the health informatics community, particularly as patients/citizens are often unable to articulate or conceptualise their requirements, but as we become more adept at understanding the health issues for people living within their own communities this challenge will become less difficult.

This research has confirmed that there are limitations in the current methods by which trials are evaluated and has demonstrated a method by which these limitations can be ameliorated. It is anticipated that the use of qualitative measures will become an accepted and integrated method of exploring nuances within controlled trials. Through adopting this type of approach the trial outcomes become better able to deal with the individual as well as the total population.

It is also important that data relating to 'failure' is collected, disseminated and embraced throughout the health informatics community rather than hidden. Through the exploration of IT 'failures' in this research it has been possible to understand some of the factors that influence people in their decisions about IT adoption and this

information can be used to improve and inform future work. Failure should be framed as a defect in the design or realisation of the intervention, rather than as a shortcoming or incapacity of the subject.

The impact of the creation of disease silos or the elevation of the importance of one disease process over another has become evident through this research. This creation of a false division between a disease and its influence upon an individual's life or the primacy given to certain symptoms over others fails to acknowledge the complexity of people's lives. This creates the possibility of attributing causal relationships that do not actually exist.

It is important for the health informatics community to recognise and confront the challenges of working within clinical paradigms. Clinical research teams often have a poor understanding of the role of health informatics, beyond that of providing a technical solution both for the intervention and for the collection of research data. It is important that the discipline takes the opportunities provided by the move towards community health informatics to establish itself as an integral part of the new models of health care and not merely a provider of technology.

Finally it is essential that there is planning and consideration of the ethics and morality of withdrawal of an intervention prior to the commencement of the intervention.

9.5 Limitations of the Study

All research methods have an inherent set of strengths and weaknesses. As part of the research process it is important to recognise and demonstrate how these limitations have been addressed within the investigation. Interpretivist research is commonly criticised for its potential to introduce bias, limited generalisability (Galliers, 1992), apparent lack of rigor and relevance (Darke, Shanks, & Broadbent, 1998; Klein & Myers, 1999), lack of control of variables and different interpretations by individual researchers/stakeholders (Galliers, 1992). The limitations of this current research are described below in terms of scope, bias, rigour and validity.

9.5.1 Scope of the research

This research was conducted within the constraints of a small clinical controlled trial with its own aims and objectives (section 2.4). This research location provided the benefit of giving the researcher access to the trial data, in addition to semi-structured interview data, thus enabling the use of a comprehensive range of evaluation techniques. However, the location within the clinical controlled trial also imposed strict limitations upon the degree of freedom available to the health informatics researcher. These limitations included the trial design; recruitment strategy; IT tool design; IT infrastructure provision; and IT tool implementation.

This highlights that there is a difference between the requirements for clinical trials and design trials when undertaking research in health informatics. This requires a distinction to be made between clinical trials and design trials and their purpose and research questions. In this case there has been a mixing or confusion between clinical and design trial and this has led to some difficulty in expressing the research outcomes in clear manner. However, when conflicting research outcomes have been

discovered the clinical research outcomes have taken precedence and this has at times imposed strict limitations upon the scope of the research.

9.5.2 Research Bias

Biases are unavoidable in case study research. The influence of the researcher conducting the research creates a bias during the data collection process. Prior assumptions and views about the research context can influence the analysis. The participant's reaction to the interviewer and interview process can cultivate various biases. The length of the interview, the emotional status of the interviewee, the type of questions and the interview setting can all contribute to possible research biases. To overcome these biases the researcher utilised the triad interviews to ensure the collection of data from multiple sources. Using multiple sources of data helps reduce the problem of potential research bias (Miles & Huberman, 1994). The case study selection process exposed very little bias other than the possible bias introduce through the participants consenting to be interviewed (section 4.4.3.1). However, as demonstrated in the interview analysis process (Chapter 6) the resulting cases represented a wide range of perspectives.

9.6 Future Research

Given the relatively small body of health informatics literature that examines the conduct and evaluation of patient-centred health informatics research from the patient's perspective there is a great deal of scope for future work in this area. In relation to the specific findings of this research, however, there are a number of projects that can be undertaken in the future:

Conduct follow up research post intervention to re-evaluate clinical and non-clinical outcomes for all these participants after the support has been removed. This research would also enable an examination of the ongoing impact of the technology introduced and whether or not the participants continued to use the technologies and tools provided to them. This would provide some initial longitudinal data on the long term effects and sustainability of effects from the current intervention as well as further the evaluation of the impact of the online patient diary and technology introduction on participant's lives.

Expand upon the current research through the introduction of a range of technologies to enable real-time self-monitoring. This could be used to understand the potential for other technologies within this disease group.

Conduct similar research using current computer technologies and fast Internet connectivity to understand the limitations, if any, imposed through the use of legacy systems within this research.

Undertake a design research project employing the principles of participant-centred and participatory design to ensure that the tools fulfilled the needs of the participants. This research could be undertaken in the course of developing a sustainable generic online symptom monitoring diary for people with COPD. This use of design methodologies would enable the researcher to gain insights into ways of engaging with chronically ill people to support them through the development process.

9.7 Concluding Reflections

At a theoretical level this thesis commenced by expressing concerns about the manner in which clinical and IT evaluations are constrained by the dominance of current evaluation paradigms with their reliance upon random controlled trials. These concerns led to 2 research questions that were examined through a three phase approach to data collection and analysis that enabled quantitative and qualitative data at individual group and cohort levels to be examined and compared as an approach for revealing the interplay of clinical, technical and social factors to assess how an IT tool impacted on patients at multiple levels.

From a theoretical perspective, this thesis has revealed the ways in which particular measurements and trial constructs constrain and potentially pre-determine the ability of researchers to understand and explain an individual patient's results, experiences and perceptions. By exploring in depth these factors and their inter-relationships at individual, group and cohort levels this thesis highlights one approach that redefines how positive and/or negative impacts/influences can be viewed.

At a methodological level, by utilising quantitative and qualitative data across multiple patient cases an approach has been developed that strengthens the validity and reliability of each individual measure and its analysis by providing context at multiple levels of abstraction; individual, group, cohort, clinical, technical and social.

At a substantive level, the results found have enabled a rich picture to be produced of individual patient experiences and clinical outcomes through a twelve month intervention and how an online patient diary acts on and in turn is responded to in both positive and negative ways such that an heuristic model to provide guidance on the range of influences, impacts and effects of IT can be more effectively managed and assessed.

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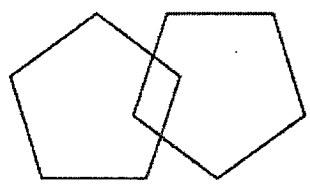
APPENDIX 1: Mini-Mental State Exam

The Mini-Mental State Exam

Patient_____ Examiner _____ Date_____

Maximum	Score	
		Orientation
5	( )	What is the (year) (season) (date) (day) (month)?
5	( )	Where are we (state) (country) (town) (hospital) (floor)?
		Registration
3	( )	Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record. Trials _____
		Attention and Calculation
5	( )	Serial 7's. 1 point for each correct answer. Stop after 5 answers. Alternatively spell "world" backward.
		Recall
3	( )	Ask for the 3 objects repeated above. Give 1 point for each correct answer.
		Language
2	( )	Name a pencil and watch.
1	( )	Repeat the following "No ifs, ands, or buts"
3	( )	Follow a 3-stage command: "Take a paper in your hand, fold it in half, and put it on the floor."
1	( )	Read and obey the following: CLOSE YOUR EYES
1	( )	Write a sentence.
1	( )	Copy the design shown.

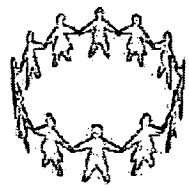


_____ Total Score

ASSESS level of consciousness along a continuum _____

Alert Drowsy Stupor Coma

APPENDIX 2: Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale



STANFORD
PATIENT EDUCATION
RESEARCH CENTER

Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

APPENDIX 3: SF36v2

Participant ID: _____ Date__ __ __

Your Health and Well-Being

This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. ***Thank you for completing this survey!***

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Participant ID: _____ Date__ __ __

3 The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐ 1	☐ 2	☐ 3
b Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
c Lifting or carrying groceries	☐ 1	☐ 2	☐ 3
d Climbing several flights of stairs	☐ 1	☐ 2	☐ 3
e Climbing one flight of stairs	☐ 1	☐ 2	☐ 3
f Bending, kneeling, or stooping	☐ 1	☐ 2	☐ 3
g Walking more than a kilometre	☐ 1	☐ 2	☐ 3
h Walking several hundred metres	☐ 1	☐ 2	☐ 3
i Walking one hundred metres	☐ 1	☐ 2	☐ 3
j Bathing or dressing yourself	☐ 1	☐ 2	☐ 3

Participant ID: _____ Date__ __ __

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. Had difficulty performing the work or other activities (for example, it took extra effort)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Participant ID: _____ Date__ __ __

6. **During the <u>past 4 weeks</u>, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. **How much <u>bodily</u> pain have you had during the <u>past 4 weeks</u>?**

None	Very mild	Mild	Moderate	Severe	Very severe
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

8. **During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Participant ID:_____ Date__ __ __

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Have you been very nervous?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. Have you felt so down in the dumps that nothing could cheer you up?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e. Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f. Have you felt downhearted and depressed?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g. Did you feel worn out?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h. Have you been happy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
i. Did you feel tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Participant ID:_____ Date_____

11. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. I am as healthy as anybody I know	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. I expect my health to get worse	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. My health is excellent	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

APPENDIX 4: Hospital Anxiety and Depression Scale

Hospital Anxiety and Depression Scale (HADS)

nferNelson

Name: Date:

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A D

I feel tense or 'wound up'
Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy
Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I can laugh and see the funny side of things
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind
A great deal of the time
A lot of the time
Not too often
Very little

I feel cheerful
Never
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach
Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic
Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or television programme
Often
Sometimes
Not often
Very seldom

Now check that you have answered all the questions

A D

APPENDIX 5: Symptom Monitoring Diary

Paper Based Diary

Diary

ID number:

Instructions:

- Please complete this diary each evening
- Each section requires you to circle the number which describes how you feel **today** compared to normal
- Please weigh yourself wearing similar clothing (or none) every Monday morning and record in the space provided. Should you forget, complete as soon as possible
- At the end of the week, post the completed diary in the prepaid envelope. Should you have mislaid envelopes or run out, post to:

Research Assistant,
Pathways Home,
Private Bag XX
Tasmanian School of Nursing and Midwifery
Hobart 7001

- If you have any further queries or problems with completion of the diary please contact <Research Assistant> by telephoning XXXX

This COPD diary has been developed by the Pathways Home: Chronic Disease Management Partnerships research team for use within the program.

You rate your normal breathlessness as.....							
Please circle the number that describes your breathlessness today							
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
much better	+3	+3	+3	+3	+3	+3	+3
moderately better	+2	+2	+2	+2	+2	+2	+2
slightly better	+1	+1	+1	+1	+1	+1	+1
no change from normal	0	0	0	0	0	0	0
slightly worse	-1	-1	-1	-1	-1	-1	-1
moderately worse	-2	-2	-2	-2	-2	-2	-2
much worse	-3	-3	-3	-3	-3	-3	-3

You rate your normal cough as.....							
Please circle the number that describes your cough today							
	Mon	Tue	Wed	Thur	Fri	Sat	Sun
much better	+3	+3	+3	+3	+3	+3	+3
moderately better	+2	+2	+2	+2	+2	+2	+2
slightly better	+1	+1	+1	+1	+1	+1	+1
no change from normal	0	0	0	0	0	0	0
slightly worse	-1	-1	-1	-1	-1	-1	-1
moderately worse	-2	-2	-2	-2	-2	-2	-2
much worse	-3	-3	-3	-3	-3	-3	-3

You rate your normal sputum as.....							
Please circle the number that describes your sputum today							
	Mon	Tue	Wed	Thurs	Fri	Sat	Sun
much better	+3	+3	+3	+3	+3	+3	+3
moderately better	+2	+2	+2	+2	+2	+2	+2
slightly better	+1	+1	+1	+1	+1	+1	+1
no change from normal	0	0	0	0	0	0	0
slightly worse	-1	-1	-1	-1	-1	-1	-1
moderately worse	-2	-2	-2	-2	-2	-2	-2
much worse	-3	-3	-3	-3	-3	-3	-3

Compared to how you normally feel,							
please circle the number for how you feel today							
	Mon	Tue	Wed	Thurs	Fri	Sat	Sun
much better	+3	+3	+3	+3	+3	+3	+3
moderately better	+2	+2	+2	+2	+2	+2	+2
slightly better	+1	+1	+1	+1	+1	+1	+1
no change from normal	0	0	0	0	0	0	0
slightly worse	-1	-1	-1	-1	-1	-1	-1
moderately worse	-2	-2	-2	-2	-2	-2	-2
much worse	-3	-3	-3	-3	-3	-3	-3

You rate your normal time spent on activity as.....minutes							
Please circle the number that relates to your activity in the last 24 hours							
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
much more	+3	+3	+3	+3	+3	+3	+3
moderately more	+2	+2	+2	+2	+2	+2	+2
slightly more	+1	+1	+1	+1	+1	+1	+1
no change from normal	0	0	0	0	0	0	0
slightly less	-1	-1	-1	-1	-1	-1	-1
moderately less	-2	-2	-2	-2	-2	-2	-2
much less	-3	-3	-3	-3	-3	-3	-3

You rate your normal use of reliever medication as.....times per day							
Please circle the number that relates to your use of reliever medication in the last 24 hours							
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
much more	+3	+3	+3	+3	+3	+3	+3
moderately more	+2	+2	+2	+2	+2	+2	+2
slightly more	+1	+1	+1	+1	+1	+1	+1
no change from normal	0	0	0	0	0	0	0
slightly less	-1	-1	-1	-1	-1	-1	-1
moderately less	-2	-2	-2	-2	-2	-2	-2
much less	-3	-3	-3	-3	-3	-3	-3

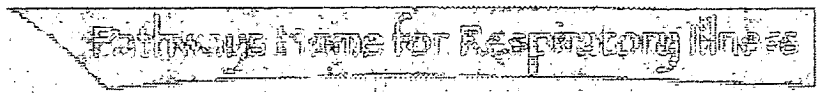
Have you visited/ been visited by any of the following?							
Please tick the box for any visits on the relevant day							
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Community Nurse							
General Practitioner							
Hospital							
Occupational Therapist							
Physiotherapist							
Home Help							
Dietician							
Pharmacist							
Social Worker							
Personal Carer							
Other.....							

Please weigh yourself on Monday and record: .....Kilograms

Please note anything that **you** think may affect the way you feel, on the day that this occurs, for example; visitors, the weather, health of your carer, family events.	
Mon	
Tues	
Wed	
Thurs	
Fri	
Sat	
Sun	

This COPD diary has been developed by the Pathways Home: Chronic Disease Management Partnerships research team for use within the program.

Online Patient Diary



Welcome to the Pathways Participant Portal, KHICHOLS

Diary Entry

Cancel | Send

Entry Date

Symptoms

Breathlessness

Much Better | Moderately Better | Slightly Better | No Change from Normal | Slightly Worse | Moderately Worse | Much Worse

Cough

Much Better | Moderately Better | Slightly Better | No Change from Normal | Slightly Worse | Moderately Worse | Much Worse

Sputum

Much Better | Moderately Better | Slightly Better | No Change from Normal | Slightly Worse | Moderately Worse | Much Worse

Feel

Much Better | Moderately Better | Slightly Better | No Change from Normal | Slightly Worse | Moderately Worse | Much Worse

Activity

Much More | Moderately More | Slightly More | No Change from Normal | Slightly Less | Moderately Less | Much Less

Medication

Much More | Moderately More | Slightly More | No Change from Normal | Slightly Less | Moderately Less | Much Less

Weight & Comments

Weight (in kg)

Diary Comments

Visits

Please click "Yes" for any visits you have made or had today

Nurse
○ Yes ◉ No

GP
○ Yes ◉ No

Hospital
○ Yes ◉ No

Occupational Therapist
○ Yes ◉ No

Physiotherapist
○ Yes ◉ No

Home Help
○ Yes ◉ No

Dietician
○ Yes ◉ No

Pharmacist
○ Yes ◉ No

Social Worker
○ Yes ◉ No

Carer
○ Yes ◉ No

Other
○ Yes ◉ No

Diary Archive

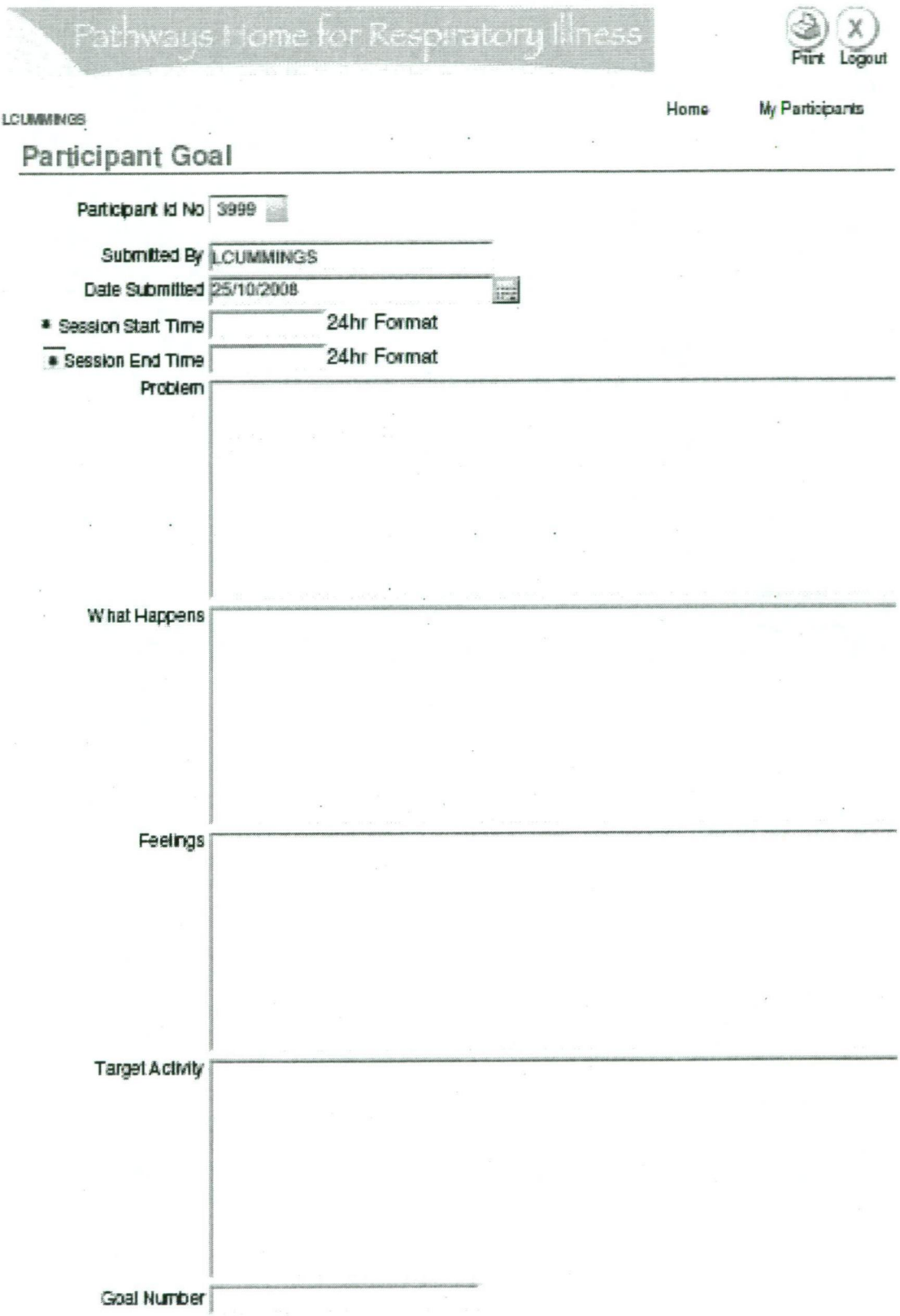
APPENDIX 6: Diary Feedback Example

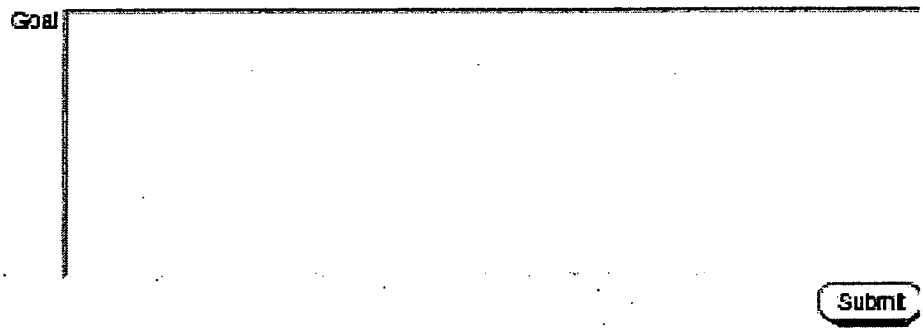
	Breathlessness	Cough	Sputum	Feel	Activity	Medication	Comments
Baseline	Normal breathlessness is unable to do most or all activities due to shortness of breath, short of breath with light tasks, and with little effort.	Normal cough is occasional cough, but less than hourly.	Normal sputum is brown, 1 tablespoon per day, and caused a great deal of inconvenience.		Normal time spent on activity is 146 minutes per day.	Normal use of reliever medication is 5.5 times per day.	
Sunday, 02 July, 2006	Much Better	Much Better	Moderately Better	Much Better	Moderately More	Slightly Less	Felt really good today. Even managed to do a baked tea. First for ages.
Saturday, 01 July, 2006	Much Better	Moderately Better	Slightly Better	Moderately Better	Moderately More	Slightly More	Feeling better
Friday, 30 June, 2006	Slightly Better	Slightly Better	Slightly Worse	Slightly Better	Slightly Less	Slightly More	Seen doctor again, chest not much better, slight fever. Still on antibiotics.
Thursday, 29 June, 2006	Moderately Worse	Slightly Worse	Slightly Worse	Moderately Worse		Moderately More	Don't last long. Breathing no bad today. So out of breath on moving.
Wednesday, 28 June, 2006	Much Better	Much Better	Much Better	Moderately Better	Slightly More	Slightly More	Felt better today, hope it lasts
Tuesday, 27 June, 2006	Moderately Better	Much Better	Much Better	Moderately Better	Slightly More	Slightly More	Antibiotics kicked in, chest not so tight. Still waiting on two tests to be done
Monday, 26 June, 2006	Slightly Better	Moderately Better	Moderately Better	Slightly Better	No Change from Normal	Moderately More	have a chest infection, my home help lady cleaned me up a lot while she was here. Such a lovely woman

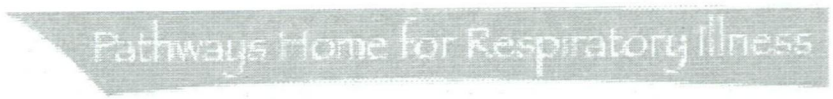
« Previous 8 - 14 Next »

Finish

APPENDIX 7: Mentoring Forms




Goal
Submit



Print Logout

LCUMMINGS

Home My Participants

Action Plan

Action Plan for Participant No. 3999

* Plan Number

Submitted By

* Date Submitted

* Goal

This week I will (do what) ?

How much ?

When ?

How many times ?

Importance 0 1 2 3 4 5 6 7 8 9 10

Confidence 0 1 2 3 4 5 6 7 8 9 10

Pathways Home for Respiratory Illness

Print Logout

LCUMMINGS

Home My Participants

Action Plan Progress

Participant No. 3999

Submitted By:

Date Submitted:

Action Plan: Do exercises for legs and deep breathing, sitting in armchai (001)

Phone Session: Yes No

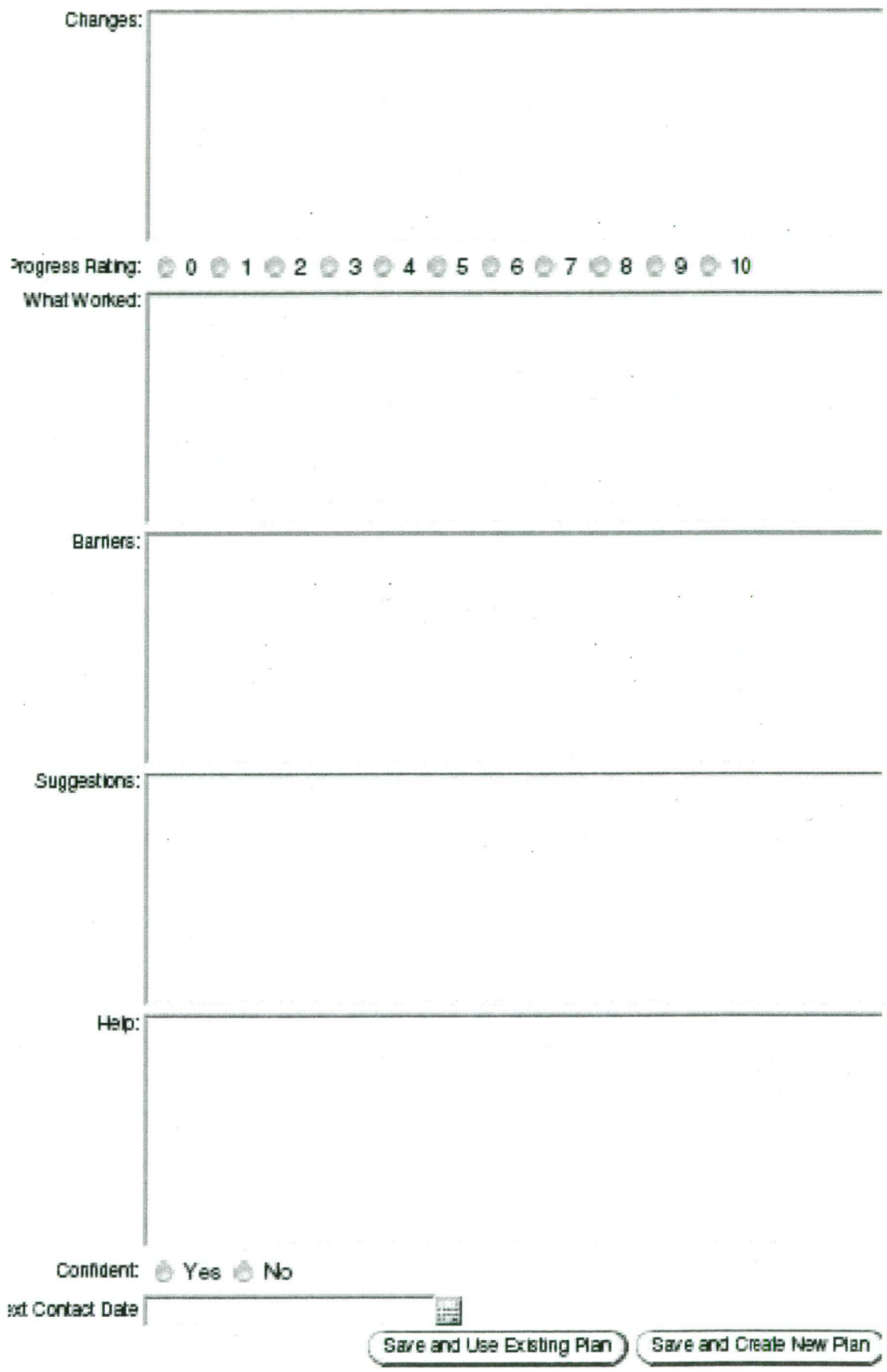
* Session Start Time 24hr Format

* Session End Time 24hr Format

Progress:

Health:

Diary:


Changes:
Progress Rating: 0 1 2 3 4 5 6 7 8 9 10
What Worked:
Barriers:
Suggestions:
Help:
Confident: Yes No
xt Contact Date
Save and Use Existing Plan
Save and Create New Plan

APPENDIX 8: Pathways Home Website User Manual

Pathways Home

Website Instructions

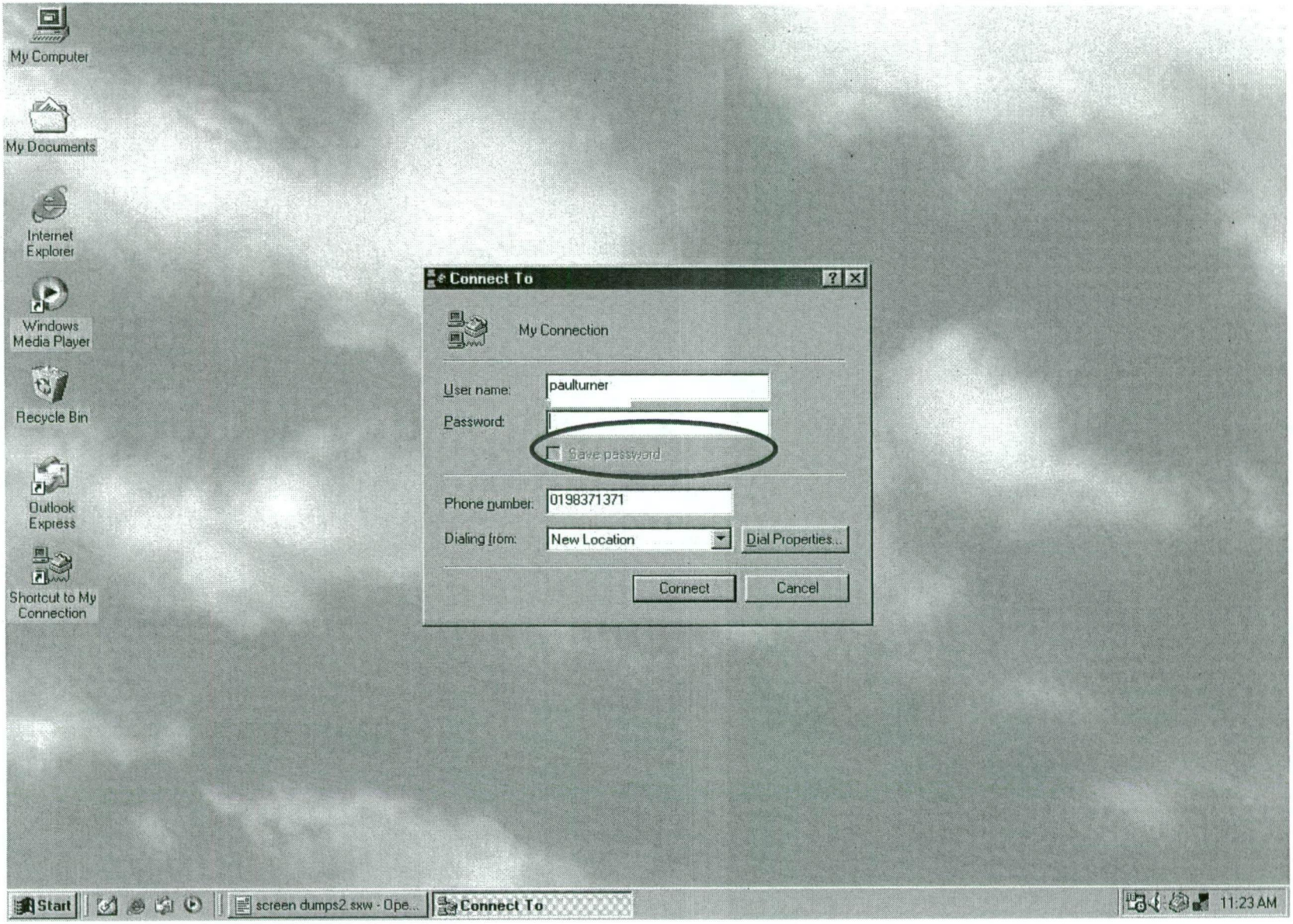
UTAS

Tasmania
DEPARTMENT of HEALTH and HUMAN SERVICES

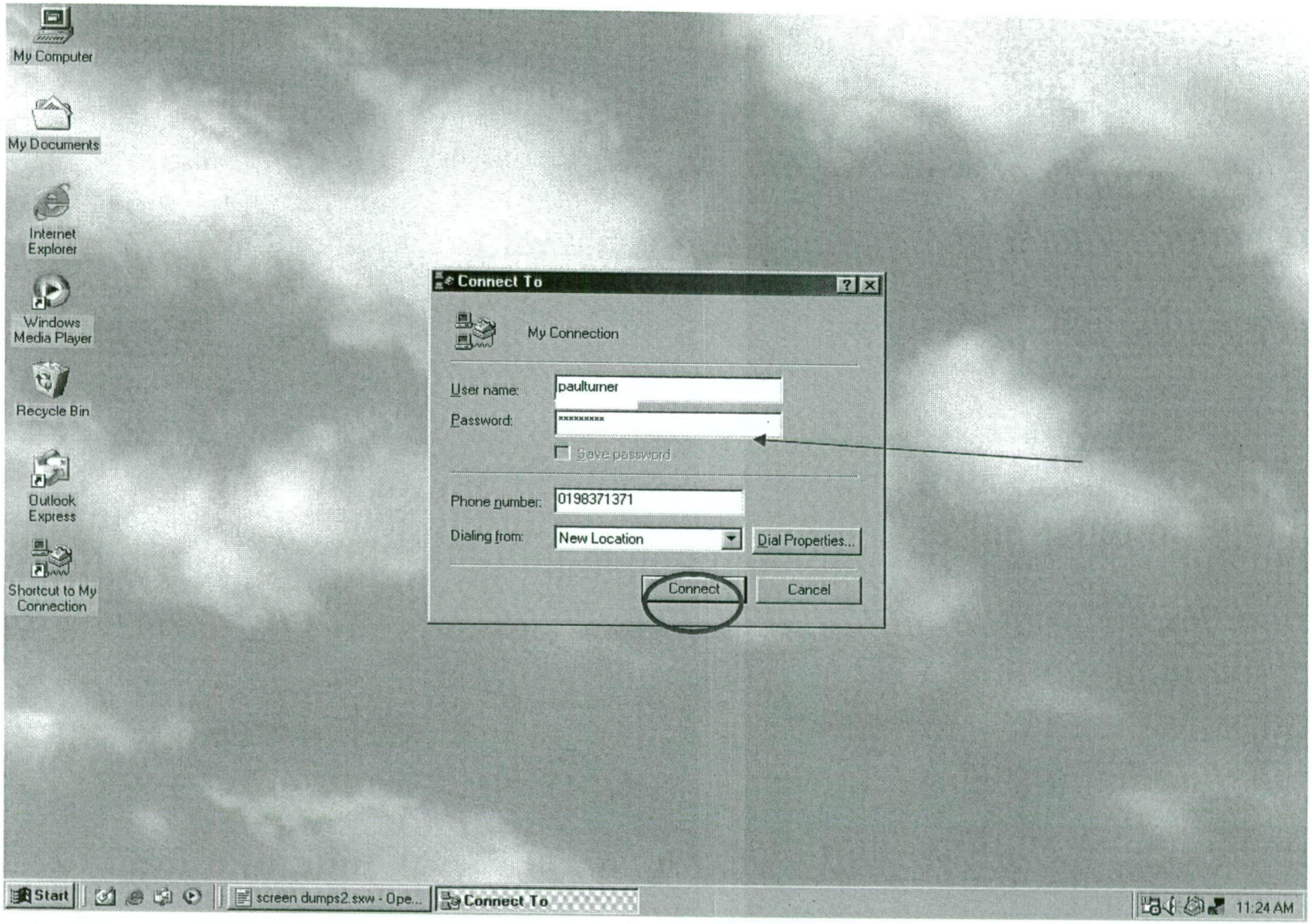
"Working together towards patient-centred healthcare"

Double click on the Connect to Internet or My Connection icon as shown below.

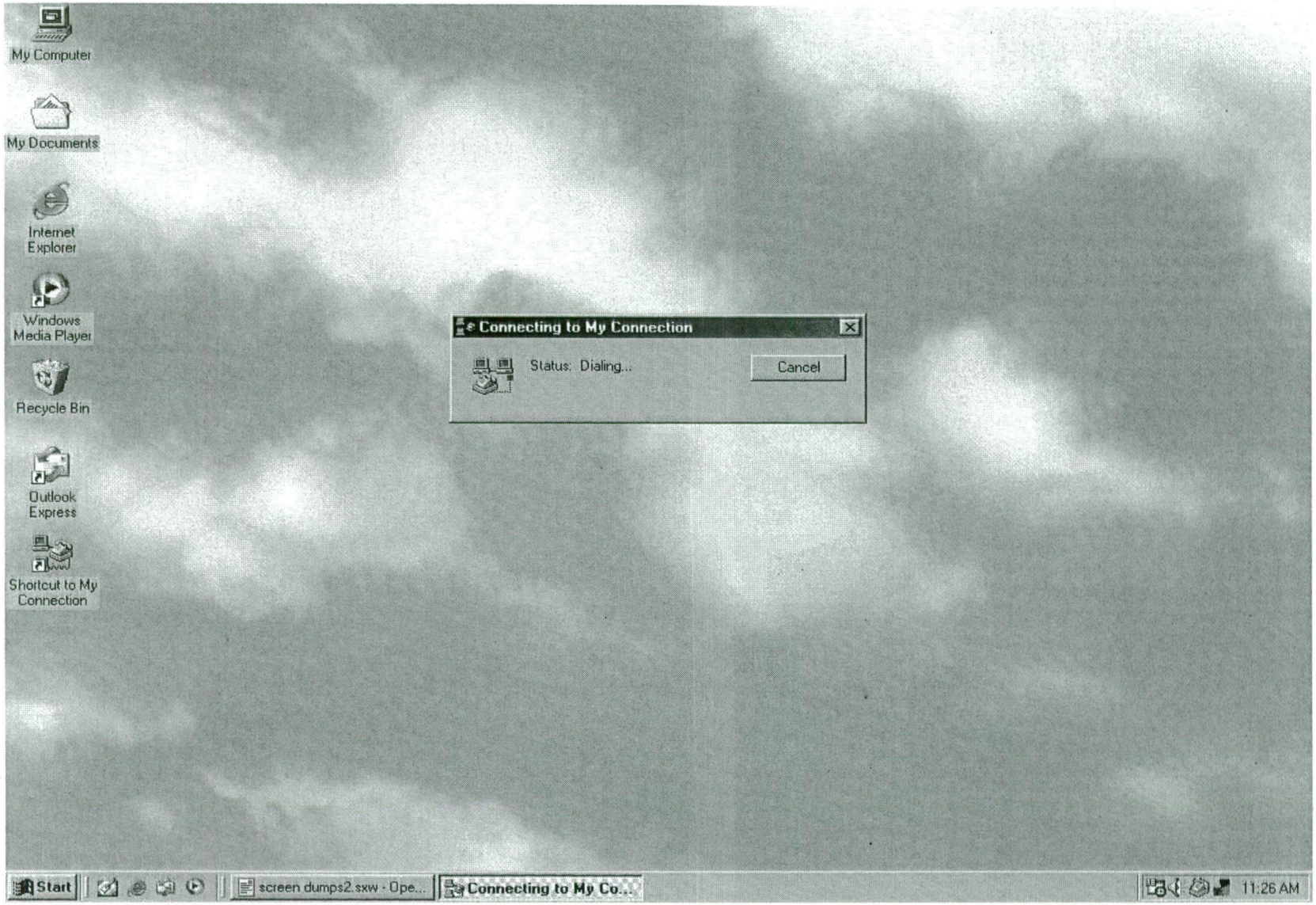
This will result in the following screen appearing. Click once in the box marked password (circled) and type in your password.


My Computer
My Documents
Internet Explorer
Windows Media Player
Recycle Bin
Outlook Express
Shortcut to My Connection
Connect To
My Connection
User name:
paulturner
Password:
Save password
Phone number:
0198371371
Dialing from:
New Location
Dial Properties...
Connect
Cancel
Start
screen dumps2.sxw - Ope...
Connect To
11:23 AM

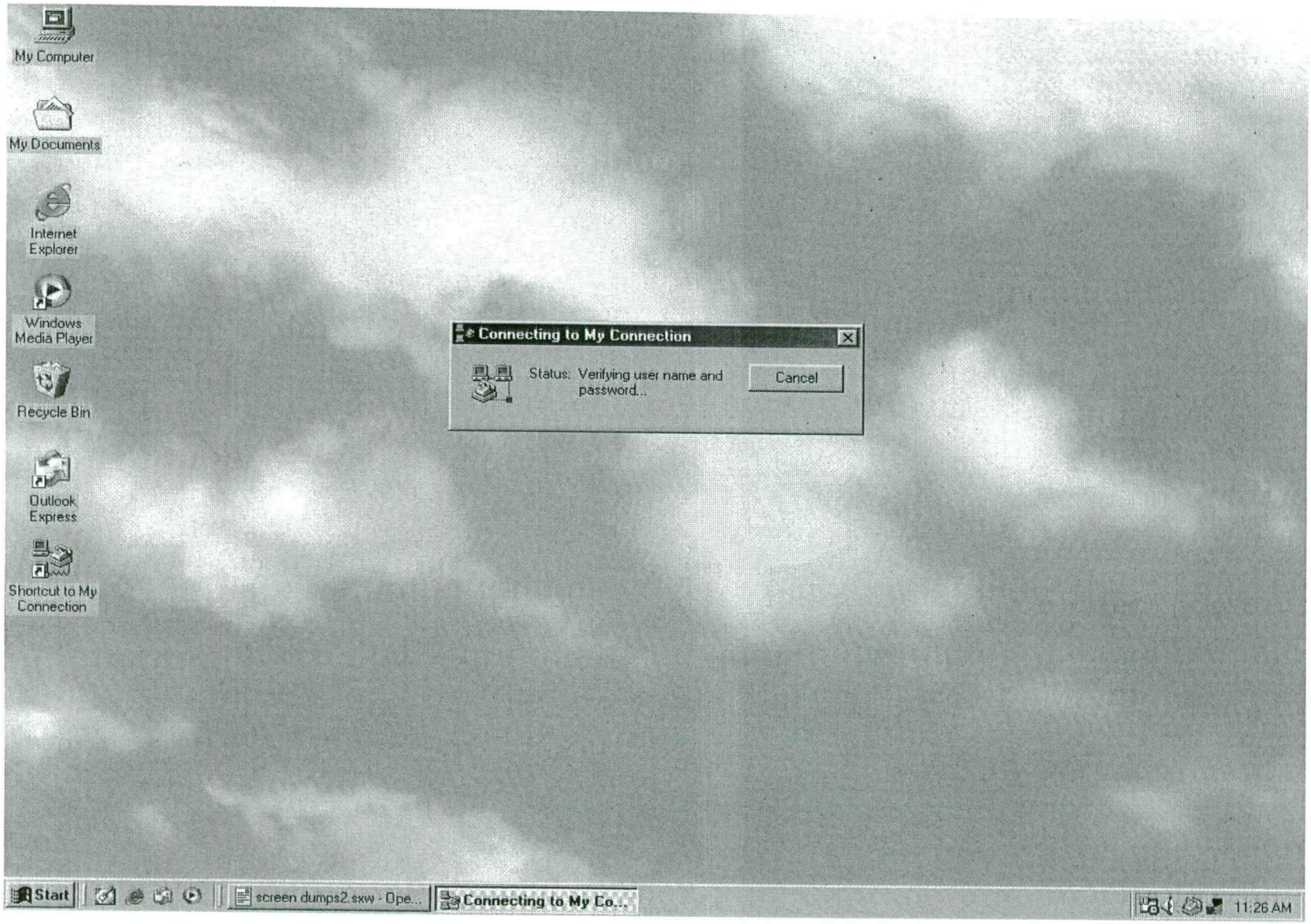
When you enter your password you should see a row of asterisks (***) appear in this box. This is to stop anyone else seeing your password. Now click the Connect button.



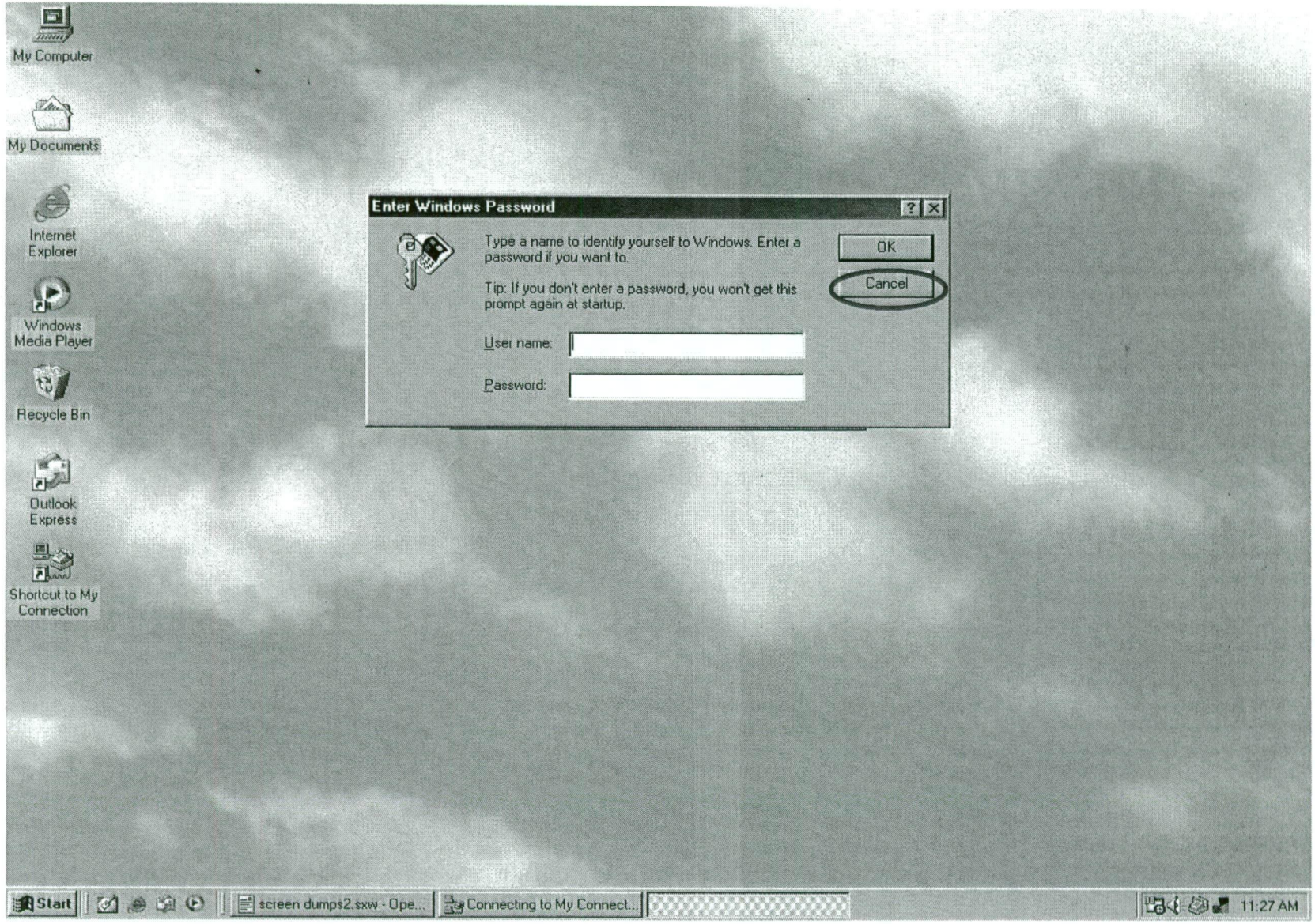
The following message should appear to tell you the computer is dialling the connection. Do not click the cancel button.


My Computer
My Documents
Internet Explorer
Windows Media Player
Recycle Bin
Outlook Express
Shortcut to My Connection
Connecting to My Connection
Status: Dialing...
Cancel
Start
screen dumps2.sxw - Ope...
Connecting to My Co...
11:26 AM

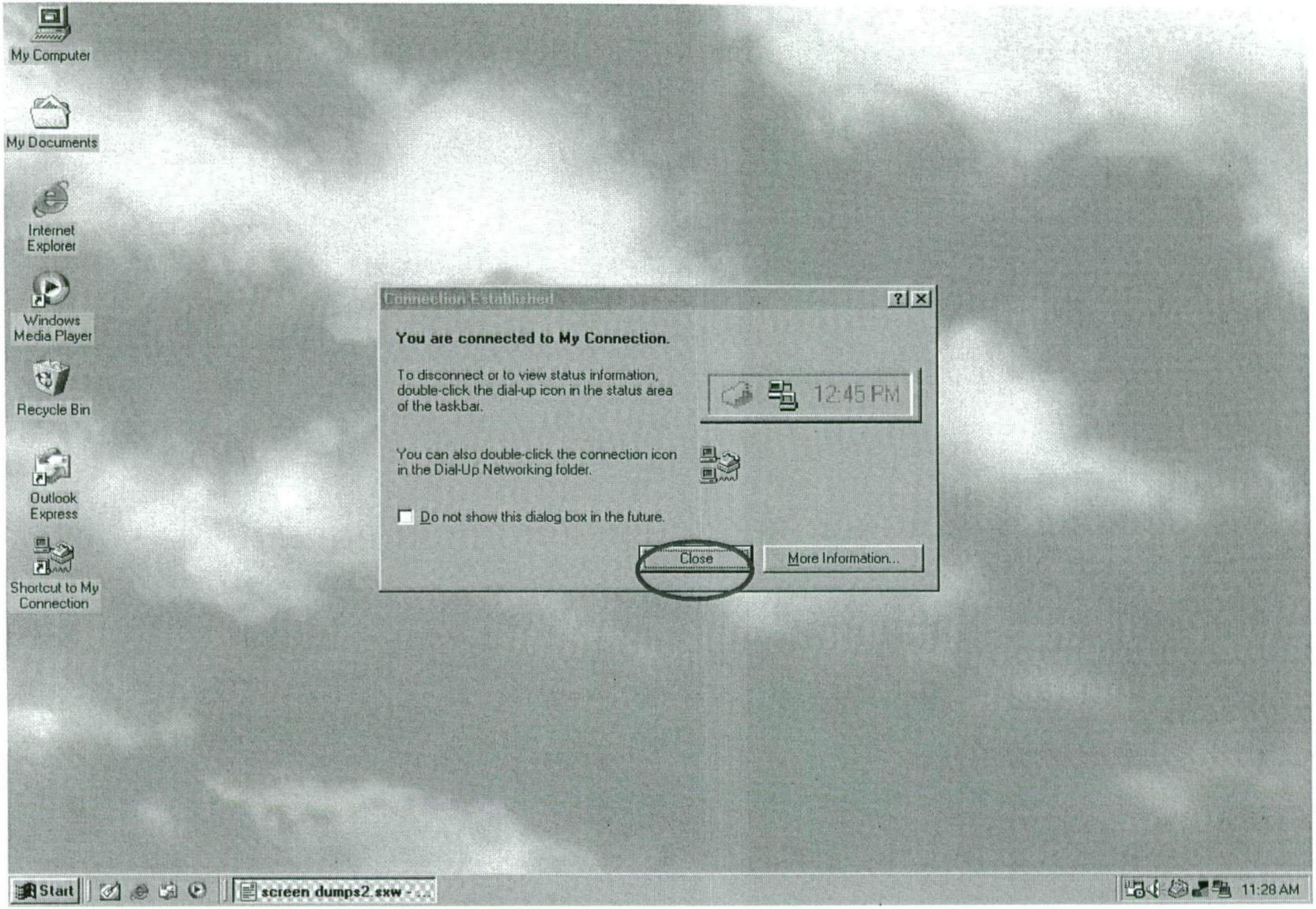
Next you should see the following message to indicate that the computer is checking your password with the connection. Do not click the cancel button. This message will disappear when you are connected.



Whenever the following message appears always click on the cancel button as there is no password set here.

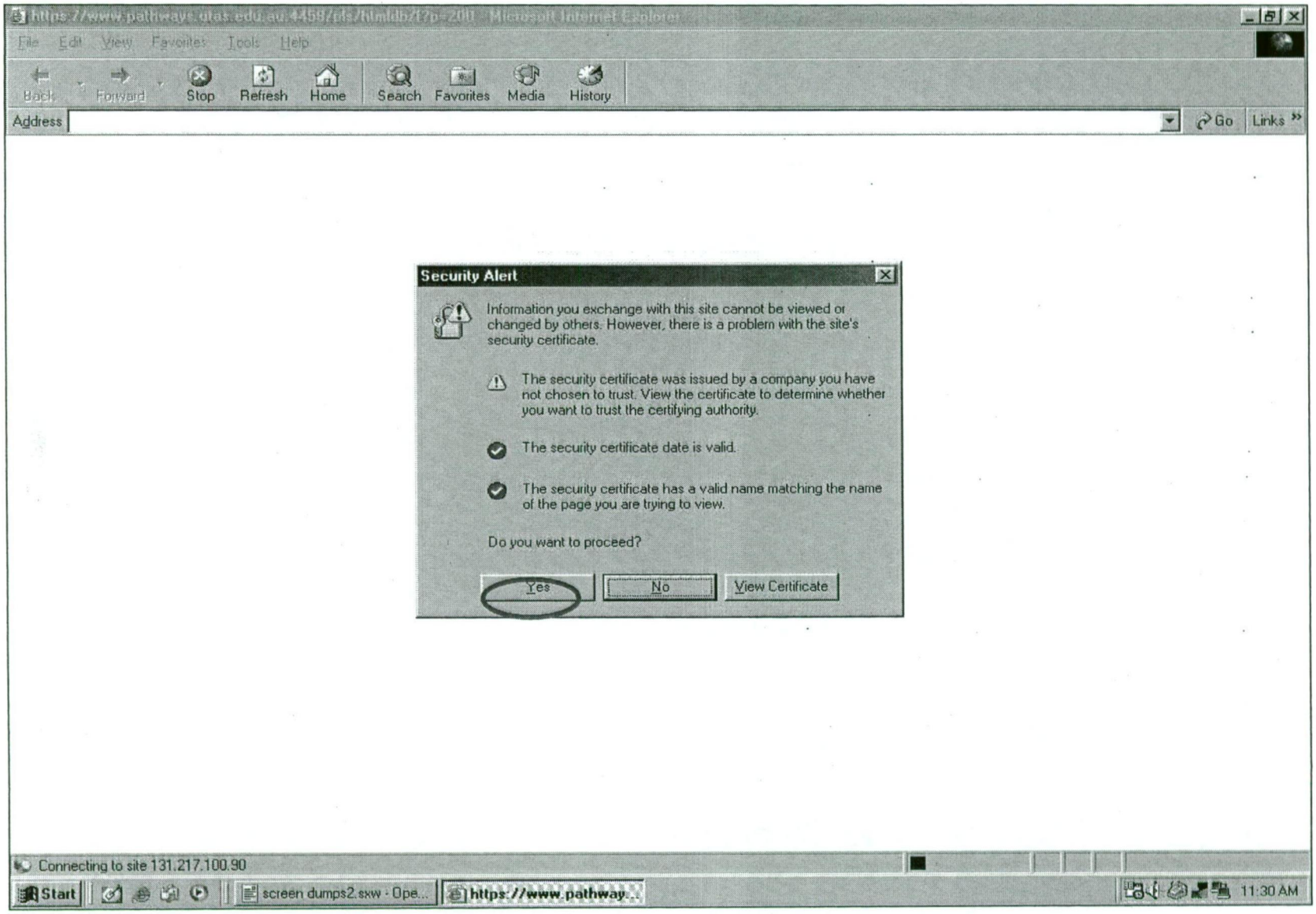


The following message indicates that you have successfully logged on to the Internet. Click the close button and you are ready to go.

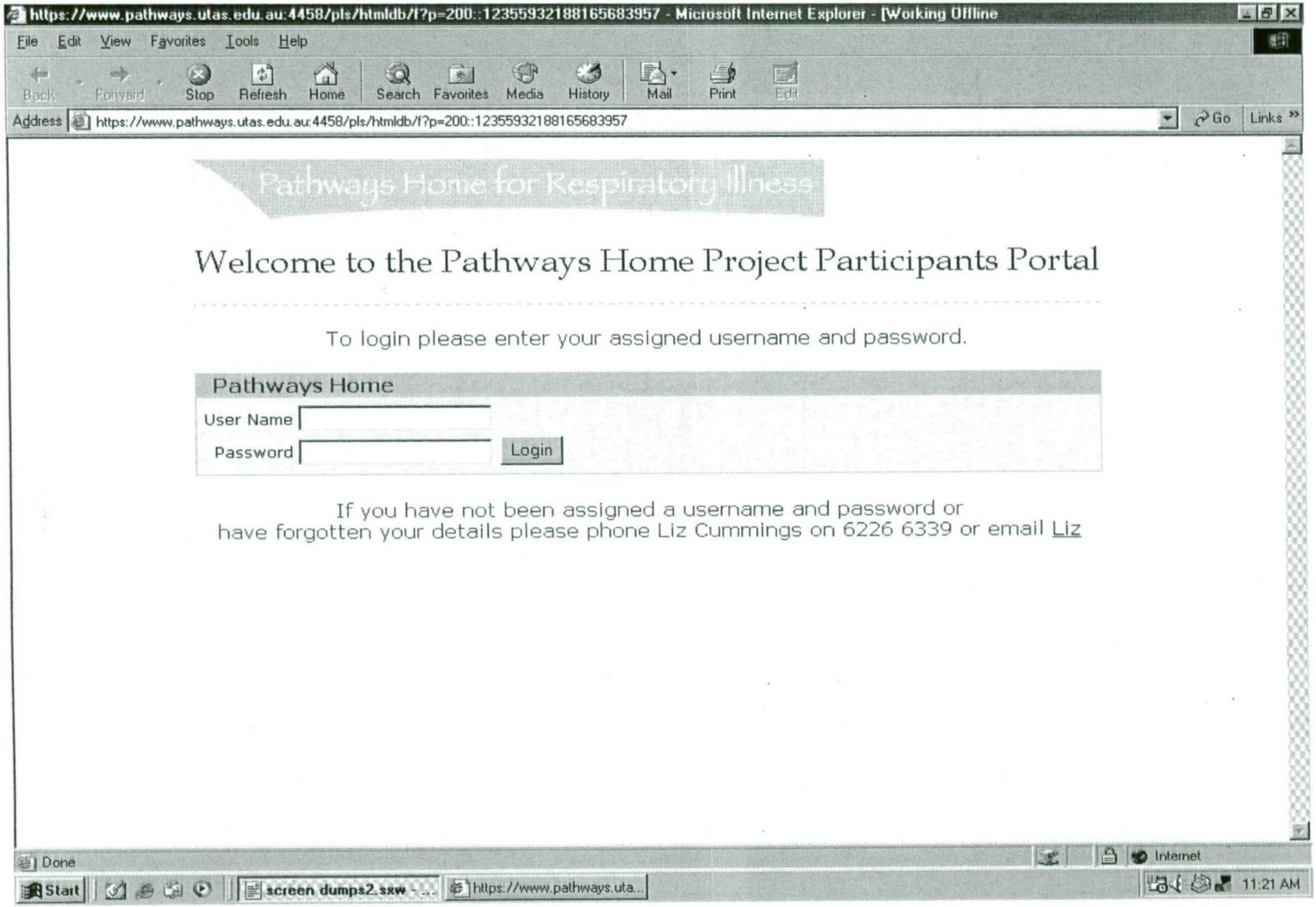


Now double click on the Internet explorer icon (circled)

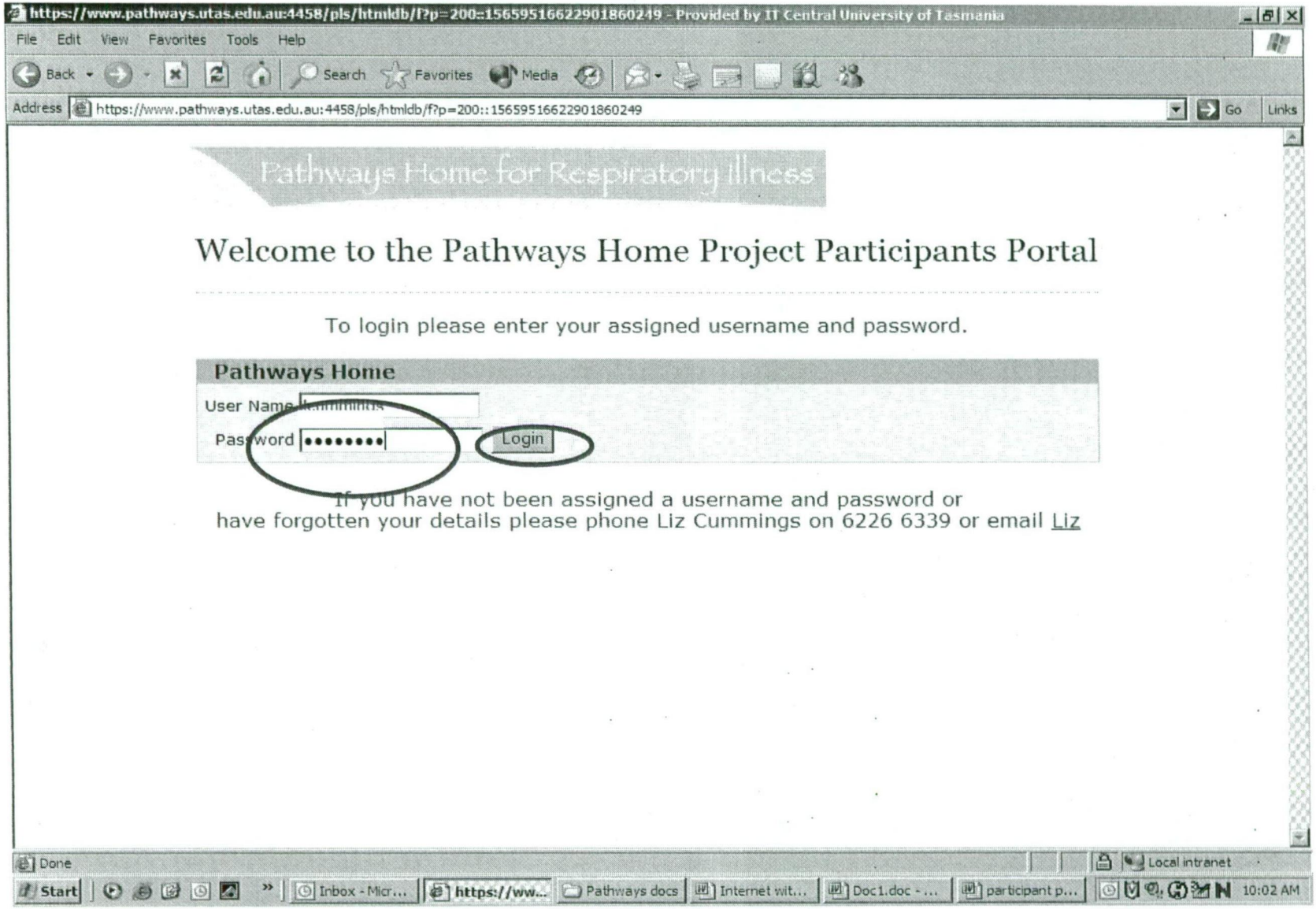
You should now see the following screen. This is telling you that you are entering a secure site. Click the Yes button.



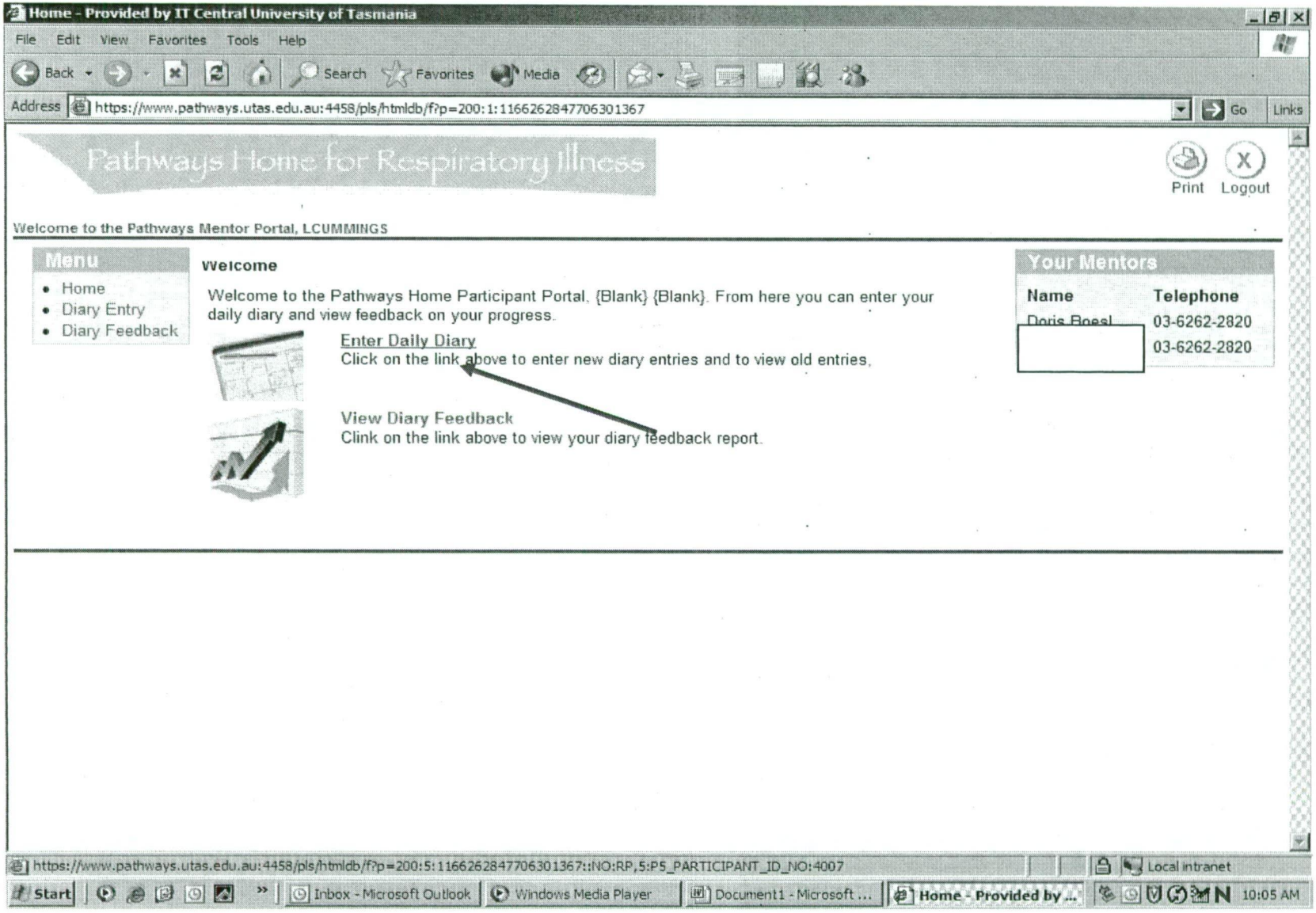
You should now be at the first page of the Pathways Home site.


https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200::1235593218816568395 7 - Microsoft Internet Explorer - [Working Offline
File Edit View Favorites Tools Help
Back Forward Stop Refresh Home Search Favorites Media History Mail Print Edit
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200::1235593218816568395 7
Go Links
Pathways Home for Respiratory Illness
Welcome to the Pathways Home Project Participants Portal
To login please enter your assigned username and password.
Pathways Home
User Name
Password
Login
If you have not been assigned a username and password or
have forgotten your details please phone Liz Cummings on 6226 6339 or email Liz
Done
Internet
Start
screen dumps2.sxw
https://www.pathways.uta...
11:21 AM

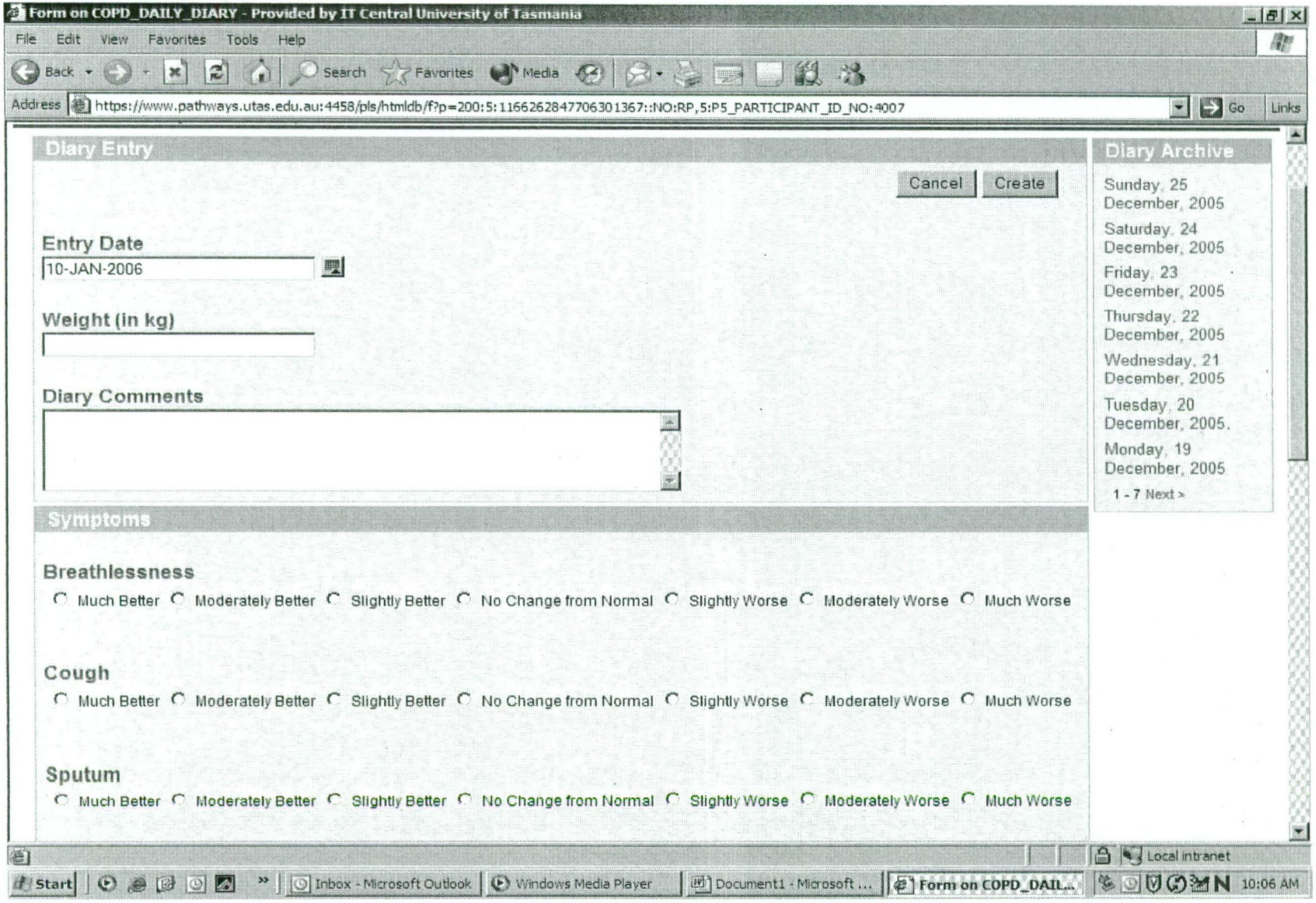
Now you need to enter your username and password. You will need to click in the box or press the tab key to move down from the top box to the lower box. Then click the login button or else hit the Enter key on your keyboard.

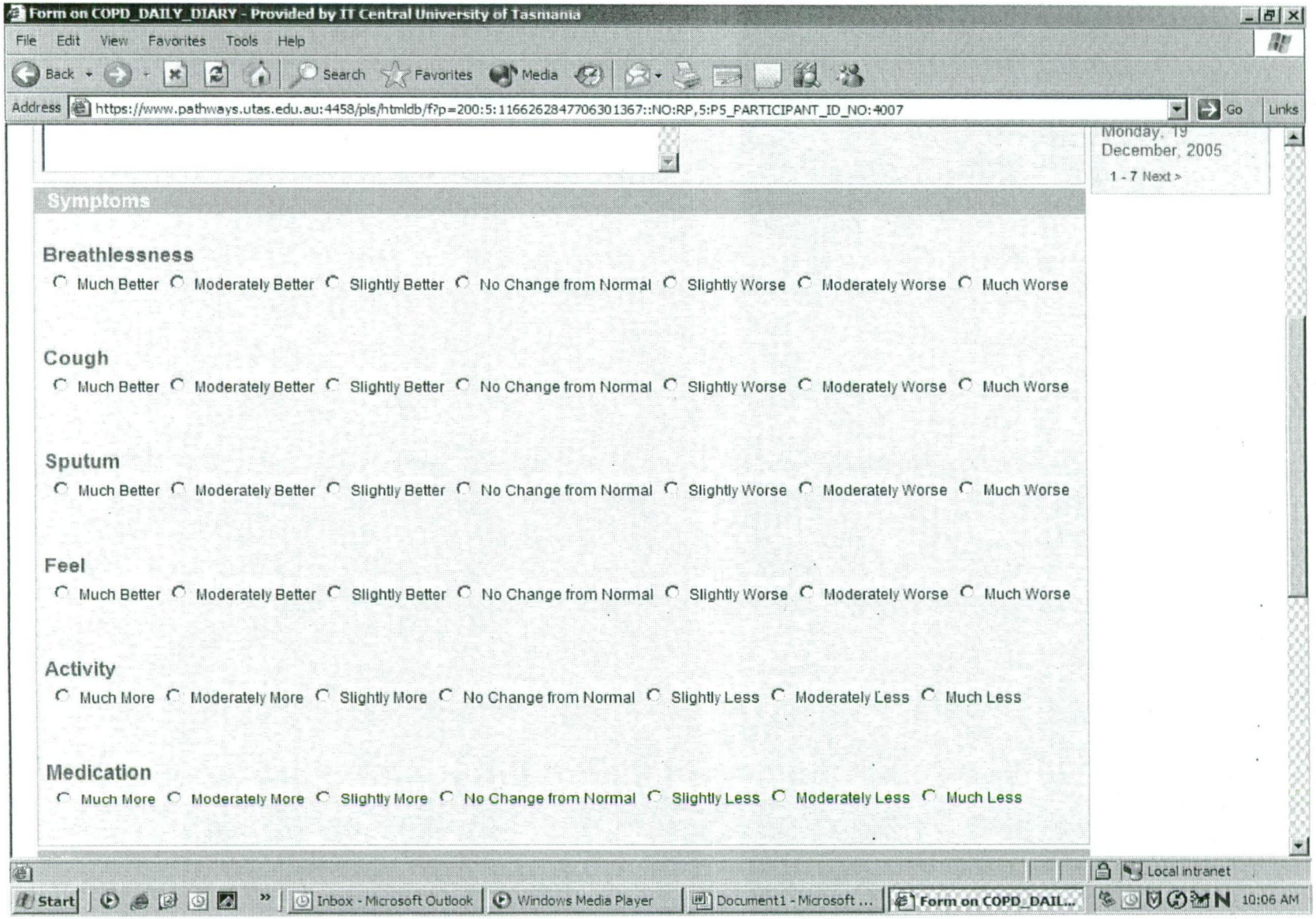

https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200::1565951662290186024 - Provided by IT Central University of Tasmania
File Edit View Favorites Tools Help
Back Search Favorites Media
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200::1565951662290186024
Go Links
Pathways Home for Respiratory Illness
Welcome to the Pathways Home Project Participants Portal
To login please enter your assigned username and password.
Pathways Home
User Name
Password
Login
If you have not been assigned a username and password or
have forgotten your details please phone Liz Cummings on 6226 6339 or email Liz
Done
Local intranet
Start
Inbox - Micr...
https://ww...
Pathways docs
Internet wit...
Doc1.doc - ...
participant p...
10:02 AM

You should now see the main page of the portal. From this page you can enter your daily diary and view the feedback. To enter your diary click on the text Enter Daily Diary as indicated by the arrow.

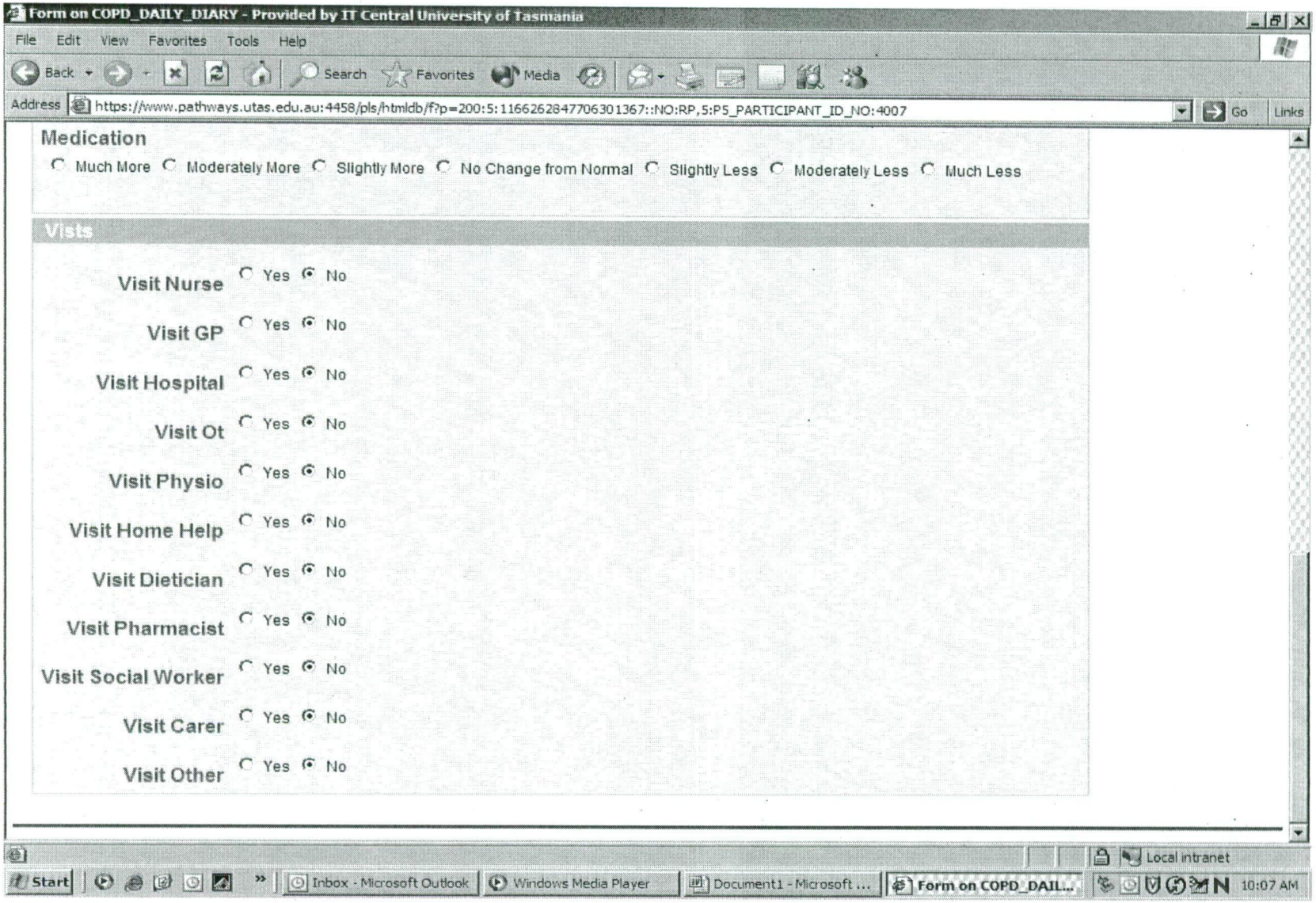

Home - Provided by IT Central University of Tasmania
File Edit View Favorites Tools Help
Back Search Favorites Media
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:1:1166262847706301367
Go Links
Pathways Home for Respiratory Illness
Print Logout
Welcome to the Pathways Mentor Portal, LCUMMINGS
Menu
Home
Diary Entry
Diary Feedback
Welcome
Welcome to the Pathways Home Participant Portal, {Blank} {Blank}. From here you can enter your daily diary and view feedback on your progress.
Enter Daily Diary
Click on the link above to enter new diary entries and to view old entries.
View Diary Feedback
Clink on the link above to view your diary feedback report.
Your Mentors
Name
Telephone
Doris Boesl
03-6262-2820
03-6262-2820
https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:5:1166262847706301367::NO:RP,5:P5_PARTICIPANT_ID_NO:4007
Local intranet
Start
Inbox - Microsoft Outlook
Windows Media Player
Document1 - Microsoft ...
Home - Provided by ...
10:05 AM

You will now see your diary. To complete it please click the text that most closely reflects your symptoms today compared with your normal symptoms. Type any comments into the comments box.

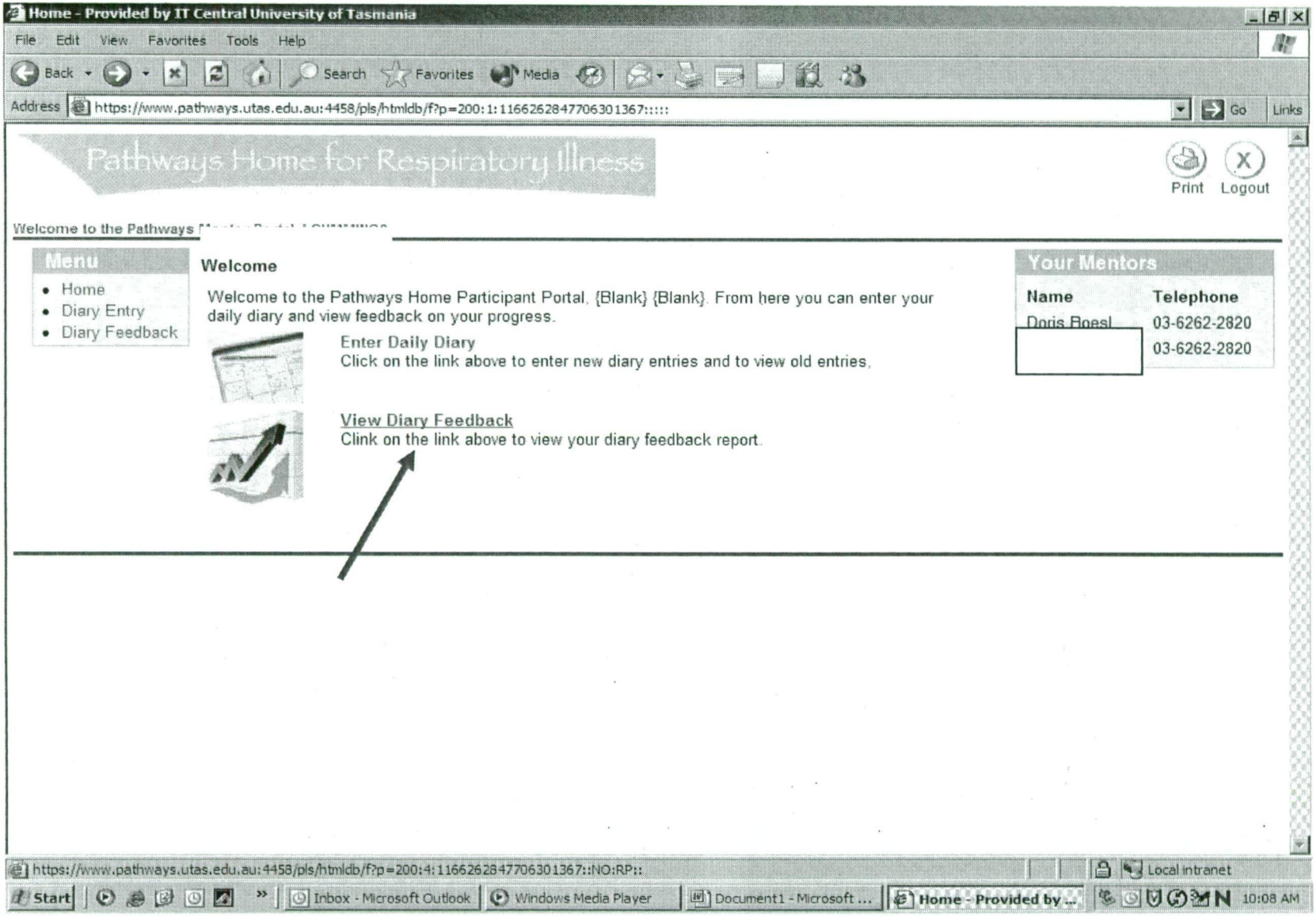

Form on COPD_DAILY_DIARY - Provided by IT Central University of Tasmania
File Edit View Favorites Tools Help
Back Search Favorites Media
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:5:11662628477063013 67::NO:RP,5:P5_PARTICIPANT_ID_NO:4007
Go Links
Diary Entry
Cancel Create
Entry Date
10-JAN-2006
Weight (in kg)
Diary Comments
Symptoms
Breathlessness
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Cough
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Sputum
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Diary Archive
Sunday, 25 December, 2005
Saturday, 24 December, 2005
Friday, 23 December, 2005
Thursday, 22 December, 2005
Wednesday, 21 December, 2005
Tuesday, 20 December, 2005.
Monday, 19 December, 2005
1 - 7 Next >
Local intranet
Start
Inbox - Microsoft Outlook
Windows Media Player
Document1 - Microsoft ...
Form on COPD_DAIL...
10:06 AM


Form on COPD_DAILY_DIARY - Provided by IT Central University of Tasmania
File Edit View Favorites Tools Help
Back Search Favorites Media
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:5:116626284770630136 7::NO:RP,5:P5_PARTICIPANT_ID_NO:4007
Go Links
Monday, 19 December, 2005
1 - 7 Next >
Symptoms
Breathlessness
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Cough
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Sputum
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Feel
Much Better Moderately Better Slightly Better No Change from Normal Slightly Worse Moderately Worse Much Worse
Activity
Much More Moderately More Slightly More No Change from Normal Slightly Less Moderately Less Much Less
Medication
Much More Moderately More Slightly More No Change from Normal Slightly Less Moderately Less Much Less
Local intranet
Start
Inbox - Microsoft Outlook
Windows Media Player
Document1 - Microsoft ...
Form on COPD_DAIL...
10:06 AM

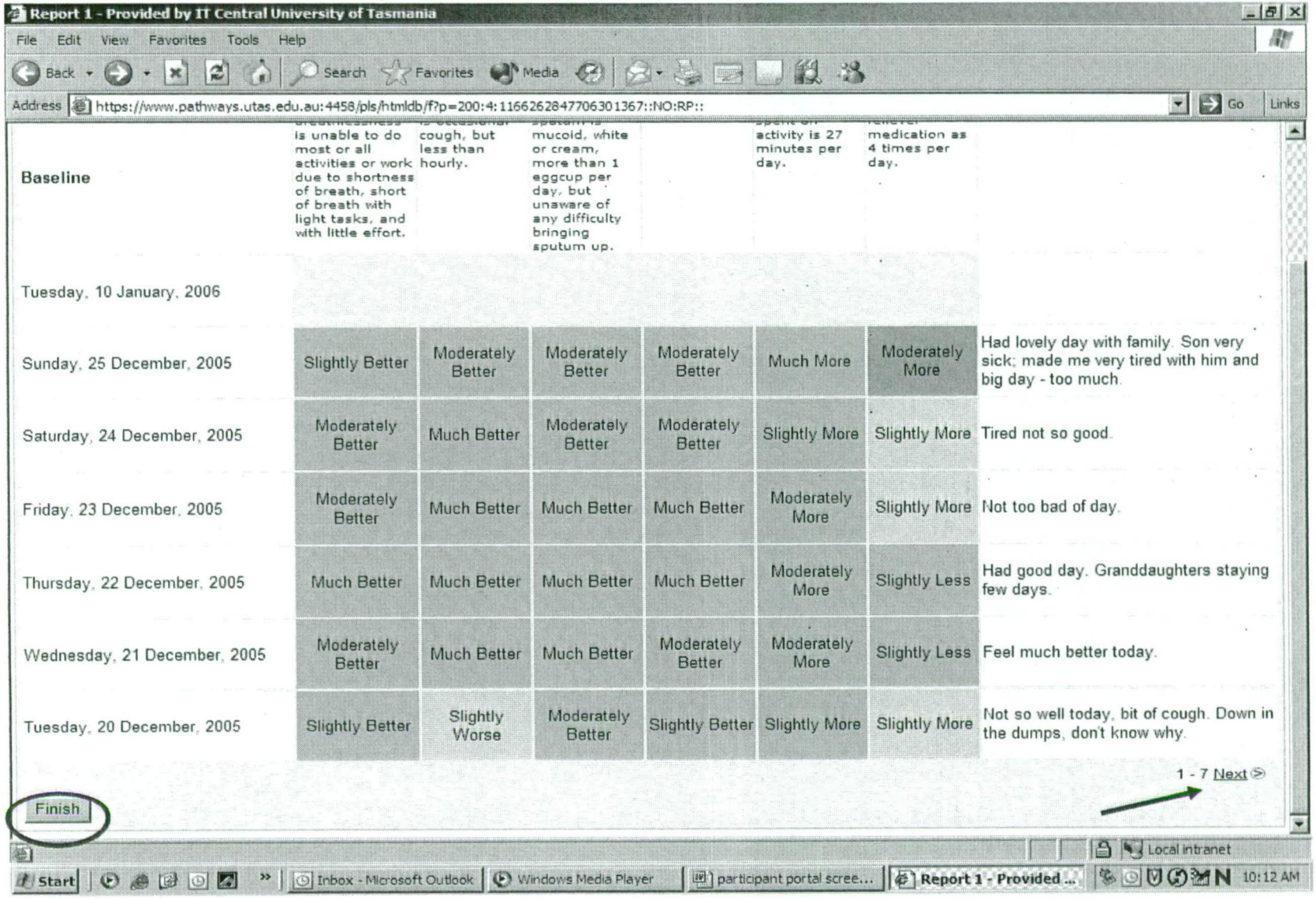
Next enter any visits to or from health professionals that you may have had today. To save this form click the create button either at the bottom right corner or top right corner.


Form on COPD_DAILY_DIARY - Provided by IT Central University of Tasmania
File Edit View Favorites Tools Help
Back Search Favorites Media
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:5:116626284770630136 7::NO:RP,5:P5_PARTICIPANT_ID_NO:4007
Go Links
Medication
Much More Moderately More Slightly More No Change from Normal Slightly Less Moderately Less Much Less
Visits
Visit Nurse Yes No
Visit GP Yes No
Visit Hospital Yes No
Visit Ot Yes No
Visit Physio Yes No
Visit Home Help Yes No
Visit Dietician Yes No
Visit Pharmacist Yes No
Visit Social Worker Yes No
Visit Carer Yes No
Visit Other Yes No
Local intranet
Start
Inbox - Microsoft Outlook
Windows Media Player
Document1 - Microsoft ...
Form on COPD_DAIL...
10:07 AM

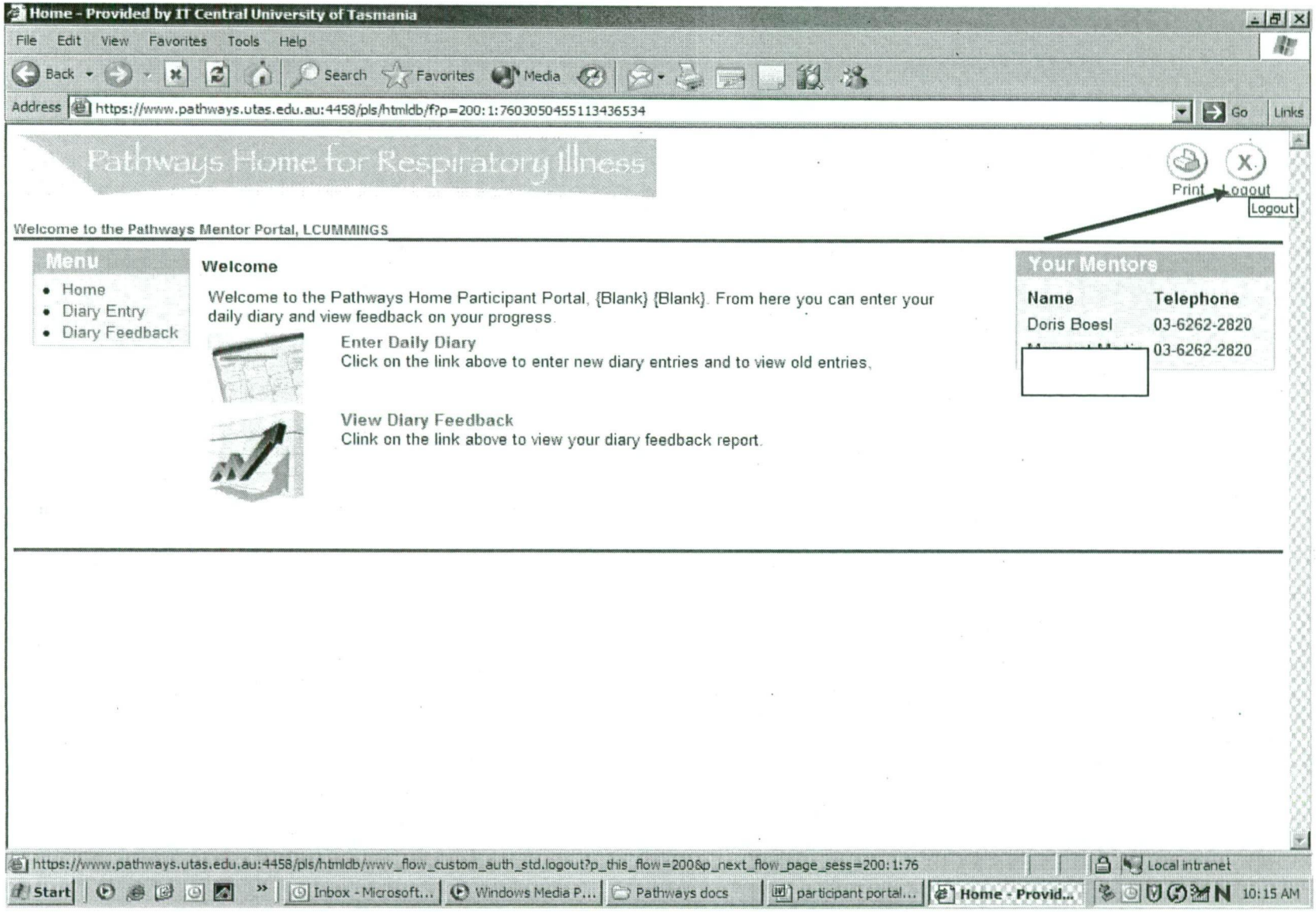
This will return you to the main page. You can now look at your diary feedback by clicking on the text saying View Diary Feedback as indicated by the arrow.


Home - Provided by IT Central University of Tasmania
File Edit View Favorites Tools Help
Back Search Favorites Media
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:1:116626284770630136 7:::::
Go Links
Pathways Home for Respiratory Illness
Print Logout
Welcome to the Pathways
Menu
Home
Diary Entry
Diary Feedback
Welcome
Welcome to the Pathways Home Participant Portal, {Blank} {Blank}. From here you can enter your daily diary and view feedback on your progress.
Enter Daily Diary
Click on the link above to enter new diary entries and to view old entries.
View Diary Feedback
Clink on the link above to view your diary feedback report.
Your Mentors
Name
Telephone
Doris Boesl
03-6262-2820
03-6262-2820
https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200:4:116626284770630136 7::NO:RP::
Local intranet
Start
Inbox - Microsoft Outlook
Windows Media Player
Document1 - Microsoft ...
Home - Provided by ...
10:08 AM

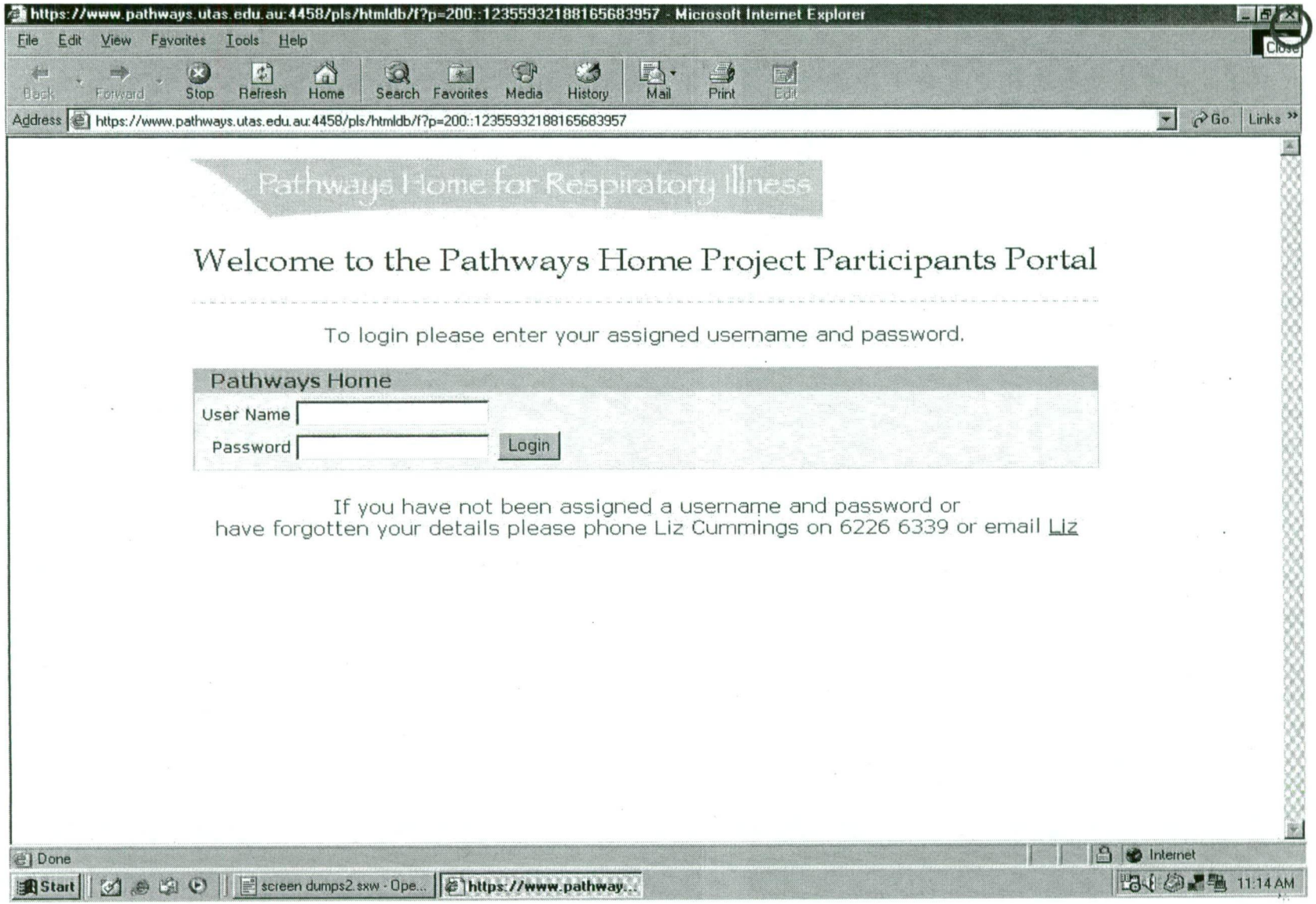
You can now see your diary feedback with today's entry at the top. To look at the previous entries click the next button in the bottom right hand side of your screen. When you have finished looking at your diary feedback click on the finish button in the bottom left corner (circled).



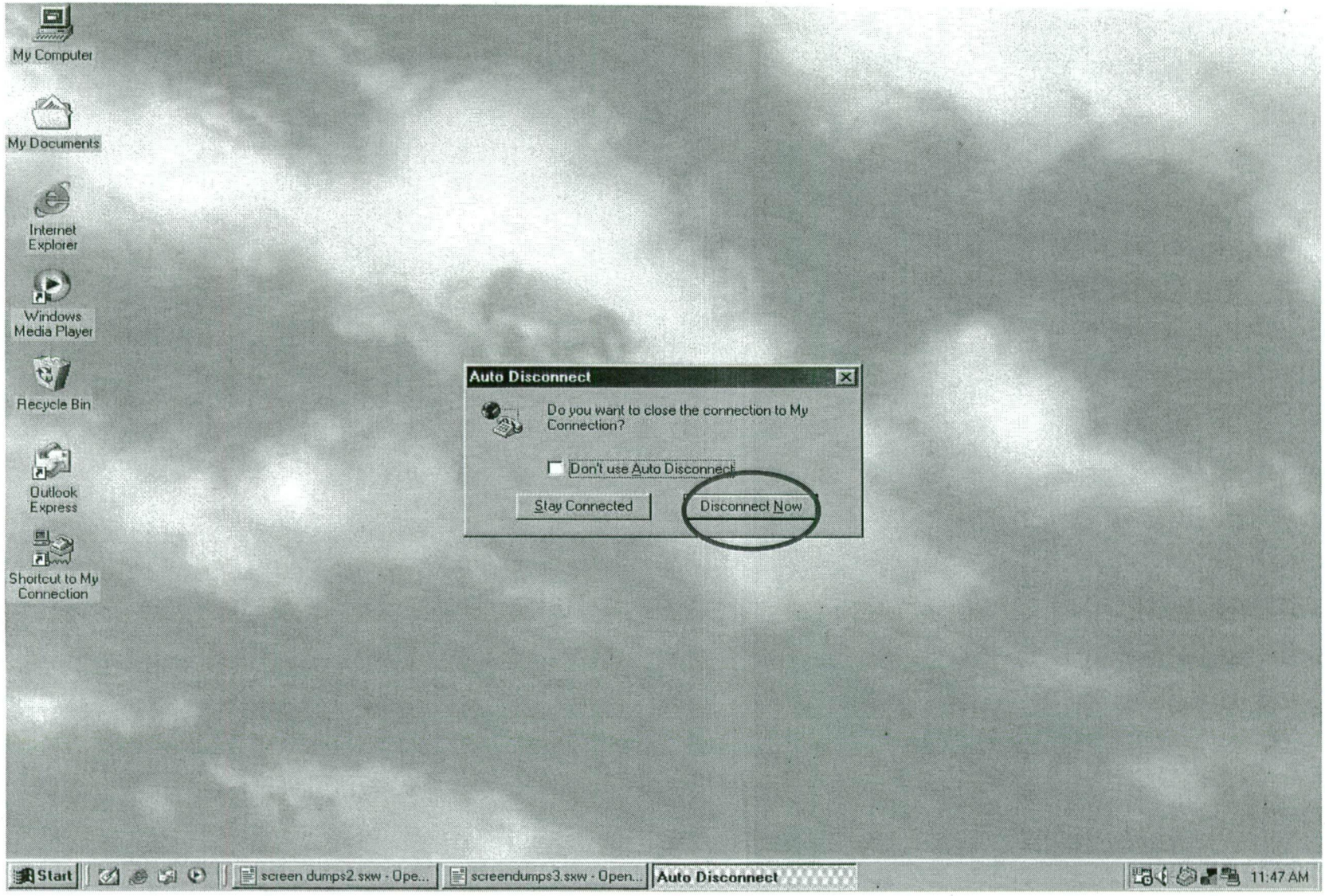
You should now see the main screen. If you have finished click on the Logout button at the top right hand corner of the screen.



To close the connection close the Internet Explorer window by clicking the cross in the top right hand corner.


https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200::1235593218816568395 7 - Microsoft Internet Explorer
File Edit View Favorites Tools Help
Back Forward Stop Refresh Home Search Favorites Media History Mail Print Edit
Address https://www.pathways.utas.edu.au:4458/pls/htmldb/f?p=200::1235593218816568395 7
Go Links
Pathways Home for Respiratory Illness
Welcome to the Pathways Home Project Participants Portal
To login please enter your assigned username and password.
Pathways Home
User Name
Password
Login
If you have not been assigned a username and password or
have forgotten your details please phone Liz Cummings on 6226 6339 or email Liz
Done
Internet
Start
screen dumps2.sxw - Ope...
https://www.pathway...
11:14 AM

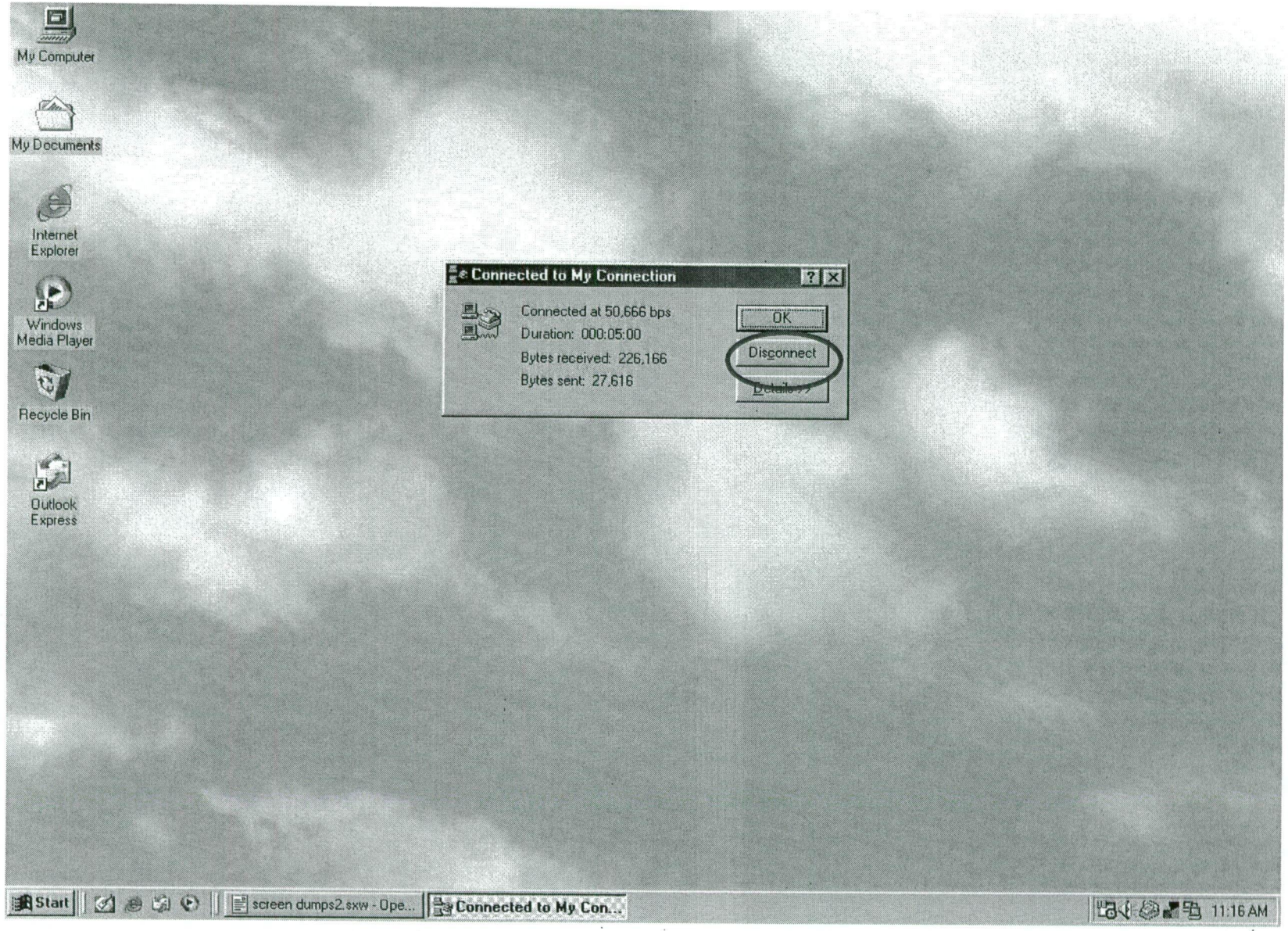
You should now see the Auto Disconnect box as below. You should click the Disconnect Now button. If you do not see this box try the steps below.



Double click on the linked computer icon (circled) in the bottom right hand side of the screen.


My Computer
My Documents
Internet Explorer
Windows Media Player
Recycle Bin
Outlook Express
Start
screen dumps2.sxw - Ope...
11:15 AM

You should now see the following box. Click the Disconnect button and this will disconnect you from the Internet.


My Computer
My Documents
Internet Explorer
Windows Media Player
Recycle Bin
Outlook Express
Connected to My Connection
Connected at 50,666 bps
Duration: 000:05:00
Bytes received: 226,166
Bytes sent: 27,616
OK
Disconnect
Details >>
Start
screen dumps2.sxw - Ope...
Connected to My Con...
11:16 AM

APPENDIX 9: Interview Frameworks

Participant Interview Questions

Section 1: Engagement with the project

- What is your understanding of Pathways Home?
- How did you get involved and why?
- What did you gain from being part of it?
- How have you found participating in the trial?
- What parts of the trial have been most useful for you?
- What has been the hardest part of being involved and why?

Section 2: Self-management and self-efficacy

- Do you think there has been any change in your general health as a result of being involved in the trial? (What?) (To what do you attribute this?)
- Has the trial changed the way you feel about managing your condition at home or making decisions about your treatment?
- Before the trial if you felt a bit of a change in your condition what did you do? Has this action changed now? What do you do now?
- With your health do you feel like it is any better through being on the program?
- How have you found using the paper diaries? Did you find it useful at all? eg writing down symptoms and thinking about them.
- Have you had any difficulty answering the questions each day? (What?) (Why?)
- How did you find the feedback graph that was posted to you? Was it helpful? How?
- How did you find the phone calls from your mentor?
- How was the goal setting and action planning useful? Why?
- Has your understanding of COPD or your health needs changed?

Section 3: IT and its role

- Did you use/think about using a computer to do your diaries?
- Were you asked if you wanted to use a computer?
- Do you remember how and why you started using the computer?
- Did you have any problems using the computer? What? How was this fixed?
- What would you change about using the computer?

- Did you feel that you had enough teaching and support with the computer?
- What was the best part about the using the computer? What was the worst?
- How useful did you find being able to see your condition plotted over time? The feedback on the computer?
- Did any of this help you change the way you manage your illness? (what?)
- Before you got the computer how much experience had you had with computers?
- What made you think that you might like to try one?
- How do you feel about the computer now?
- When you do the diary on the computer do you look at the weekly feedback chart? Do you use this information? Is it presented in a useful form for you?
- What do you think the future of the computer is with you?
- Do you use the computer for anything other than Pathways?
- Has this experience altered your general impressions of computers?
- Anything we can do to improve the computer side of it for you?
- How convenient have you found using the computer?

Section 4: Conclusion

- Do you have any suggestions for us about what we have done with the project? What might have made it better for you?
- Can you give any examples of where it has changed the way you look at your health?
- Is there anything that you would like to add?

Mentor Interview Questions

Section 1: About you and the program

1. Why did you become a mentor?
2. What was your understanding of the project when you started? Has this changed?
3. How have you found the program, being in it so far?
4. What has been good?
5. What has been bad?

Section 2: Computer experiences

6. What sort of experiences have you had with computers before?
7. Do you actually use computers here much?
8. So now with the project how have you found the IT side of the project?
9. Tell me about your frustrations or experiences with it?

Section 3: Individual Participant

10. What can you tell me about your participant and their experiences /development?
11. How much understanding do you think the participant had of the project at the beginning?
12. Has this changed?
13. Do you think their understanding of COPD has changed at all?
14. Has your participant continued to do their diaries?
15. Have you discussed with them the feedback charts?
16. Have they used the computer?
17. Did you ask them about using a computer?
18. What was their response?
19. Have you actually talked to them much about the computer?
20. Do you know if they use the computer for other things?
21. Do you think the participant is benefiting from the program? In what way?
22. What are the barriers?
23. How do you find mentoring this person?
24. How is it making action plans?
25. Does this participant ever say anything to you about their quality of life?

Research Assistant Questions

Section 1: General one off questions

1. How did you get involved in the project?
2. What is your understanding of what the project is trying to achieve?
3. What have been your duties in relation to the project?
4. How much training have you had for this role?
5. Do you interpret the questionnaires as they are done?
6. What have your experiences been with computers?

Section 2: For each individual participant

7. Can you tell me about your first visit with this person?
8. What were your general impressions about them?
9. How well did you think they understood the program?
10. Over the period that you have been visiting has there been any change in their attitude towards the program or the way they talk about their health or treatment?
11. Did you talk with them about the diaries and diary feedback?
12. Did they talk about the mentoring at all?
13. Did you observe any changes in their self-management skills over the period you were visiting?
14. Have you talked with this person about using a computer? What was their attitude?
15. Do you have anything that you have noted about this person in relation to the project that you would like to share?
16. Have you seen any changes in health behaviour in the last year?
17. Is there anything else that you can think of in relation to this person or their experiences with the project?

APPENDIX 10: Axial Codes and Core Categories

Axial Codes	Non-IT Group																		IT Group																		Core Categories
	Case A			Case F			Case G			Case H			Case I			Case K			Case B			Case C			Case D			Case E			Case J			Case L			
	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	P	M	RA	
Health Behaviour	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Personal Experience
Health General	✓	✓		✓			✓		✓										✓			✓	✓					✓			✓			✓				
Health Impact	✓	✓	✓	✓			✓	✓		✓	✓								✓			✓	✓					✓			✓			✓				
Health System																✓	✓		✓									✓		✓	✓							
Health Understanding		✓	✓	✓	✓	✓		✓		✓	✓			✓		✓	✓	✓	✓	✓		✓	✓			✓		✓		✓	✓	✓		✓	✓			
Support Mechanisms																✓			✓				✓			✓					✓	✓	✓	✓	✓			
Diary Outcome	-			-			-			-			-			-			+			-			+			-			+			+	+		Outcome
Health Knowledge		-								+	+					+	+		+	+			-		+			-	+	-	+	+		+	+	+	
Project Impact	-	-	-	-	+	+	+	+	±	-	+	-	+	+	+	+	+	+	+	+	+	-	±	-	+	+	+	-	+	-	+	+	+	+	+	+	
Self-management Behaviour		-	-		+									+		+	+		+	+	+	-	-		+	+			+		+	+	+	+	+		
Self-management Knowledge																															+	+	+					
Diary Feedback	-	+		-	+		-	+		-	+		-	+		-	+		+	+		-	+		+	+		-	+	-	+	+		+	+		Project Experience
Diary Use	-			-	-		-															-		+	+						+			+			
Goal Setting		-									-		-						-				-		-				+		-			-	-		
Mentoring Process	+	-		+							+		+			+	+		+			+	+		+			+	+		+	+		+	+	+	
Project Impression	-	±	-	-	+		-	+		-			-	+		+	+	+	+	+	+	-	+		+	+	+	-			+	+		+	+	+	
Project Knowledge	-	-	-	-		-	-	-	+	-		-	-	-	-	+	+	+	±	+	+	±	-	-		+		-			+	+	+	+	+	+	
Project Reason	-			-			-			-				+		+			+			-	-		±			-			±			+			
Symptom Monitoring	-			-			-			-	+		-			-	+		+	+		-			+	+		-	+		+	+		+	+		
Computer Attitude				-						+	+	+										+		+	+	+		±	+		+			+		+	Technology Experience
Computer Experience	-			-	-		-				-		-			-			-			+	-		-			-	-		+	-		-	-		
Computer Impact																			-	-	-	+	+	+	+	+	+	±	+	+	+	+	+	+	+	+	+	
Computer Initiation	-	-	-	-	-	-	-	-	-	±	±		-	-	-	-	-	+	+			+			+			+	-		+	+	+	+	+		
Computer Issue																			-			-			-							-	-		-			
Computer Rejection	-	-		-	-	-	-	-	-							-			-	-	+																
Computer Use																						+	+	+	+	+	+	+	+		+	+	+	+	+		